

# **Online Social Support in the Saskatchewan Heart Failure Network: An Interpretive Description Approach**

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By

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## ABSTRACT

The management and prevention of cardiovascular disease is one of the most significant challenges to the health care system, both nationally and internationally. Health 2.0 is a term that denotes the use of web-based tools by health care professionals to communicate with patients, collaborate with other health professionals, and provide health information. The purpose of this interpretive description research study was to explore the factors that have and will continue to influence or contribute to caregivers' use of social networking as a form of social support when a family member is learning to live well with heart failure. The researcher created, designed, and developed a social networking site for caregivers. Following focus group sessions with health care professionals, the Living Well with Heart Failure NING site was reviewed and approved for use. Six caregivers participated on the website and were interviewed before and after participation. The results of this research study provided an insight into the factors that have contributed to the caregivers' search for online sources of health information and peer support. The caregivers' and health care professionals' perceived consequences of utilizing online resources and social support are also identified. Health care professionals and caregivers found the social networking site easy to use, recommended the use of a moderator, and stressed the need for reliable and trustworthy information. Recommendations for health regions, health care professionals, caregivers, web developers and nurse educators are provided along with implications for nursing practice.

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## **List of Abbreviations**

<b>CNA</b>	Canadian Nurses Association
<b>CVD</b>	Cardiovascular disease
<b>HFC</b>	Heart Function Clinic
<b>HIPA</b>	Health Information Protection Act
<b>HON</b>	Health on the Net
<b>ICD</b>	Implantable Cardiac Defibrillator
<b>NCSBN</b>	National Council of State Boards of Nursing
<b>NYHA</b>	New York Heart Association Classification
<b>WHO</b>	World Health Organization



## **Glossary**

<b><i>Anonymity</i></b>	An inability of other individuals to identify an individual (Yoon & Rolland, 2012)
<b><i>Caregivers</i></b>	A family member or friend designated by the patient as being the person primarily involved in the care of a patient with heart failure at home (Hwang et al., 2011)
<b><i>Congestive heart failure</i></b>	Occurs when the heart's pumping becomes less efficient and fluid starts building up in the lungs, liver, gastrointestinal tract, and peripherally in the arms and legs (Bouffard & Kaan, 2014)
<b><i>Description</i></b>	Itemizing or documenting something as it is observed (Thorne, 2008)
<b><i>Heart failure</i></b>	Is a progressive syndrome in which the left ventricle dilates, hypertrophies, and becomes more spherical. It begins with a primary event that results in a loss of myocardium or an excessive overload on the muscle (Wagner, Johnson, & Hardin-Pierce, 2010). The cardiac muscle hypertrophies to sustain the increased workload to the heart. When the muscle can no longer maintain this increased workload, the left ventricle dilates. Many conditions can trigger heart failure such as hypertension, diabetes, hypercholesterolemia, coronary artery disease, valvular heart disease, peripheral vascular disease, illicit drug use, alcohol abuse, and rheumatic fever (Wagner et al.). The presenting signs and symptoms of heart failure include dyspnea and fatigue that limit exercise tolerance.
<b><i>Interpretive</i></b>	"Appreciating experience from the perspective of others, while simultaneously accounting for the cultural and social forces that may have shaped that perspective" (Thorne, 2008, p. 49)
<b><i>Interpretive description</i></b>	"Recognizes that the clinical mind tends not to be satisfied with 'pure' description but rather seeks to discover associations, relationships and patterns within the phenomena that has been described" (Thorne, 2008, p. 50)
<b><i>NING</i></b>	Is a free social networking platform that allows users to create a community where individuals with common interests come together online (NING, 2016)

<b><i>Online social support</i></b>	"The cognitive, perceptual, and transactional process of initiating, participating in, and developing electronic interactions or means of electronic interactions to seek beneficial outcomes in health care status, perceived health, or psychological processing ability." (LaCoursiere, 2001, p. 66)
<b><i>Self-care</i></b>	A process involving the choice of behaviors that maintain physiologic stability, and the response to symptoms when they occur (Riegel & Carlson, 2004)
<b><i>Self-management</i></b>	Requires active participation by the patient to adhere to treatment, perform self-monitoring, to maintain lifestyle modifications, and recognize symptoms (Smeulders et al., 2009)
<b><i>Social media</i></b>	Interactions among people in which they share, create, and exchange information using Web 2.0 tools (Boyd & Ellison, 2008)
<b><i>Social networking</i></b>	Web-based and mobile platforms that allow users to set up and share conversations with other users or the public and build a relationship with strangers (Boyd & Ellison; Kolowitz et al., 2014)
<b><i>Web 2.0</i></b>	The second stage of the world wide web development with a movement away from static web pages to more user-generated content as well as social media (O'Reilly, 2005; Fraser, 2011)

## **CHAPTER ONE**

### **Introduction and Review of the Literature**

#### **1.1 Introduction**

The management and prevention of cardiovascular disease [CVD] are significant challenges to the health care system, both nationally and internationally. Cardiovascular disease includes disorders of the heart and blood vessels that may result in a variety of diseases such as coronary artery disease, cerebral vascular disorder, peripheral vascular disease, hypertension, and heart failure. Globally, CVD is the leading cause of death amongst adults, resulting in more deaths than any other disease process (World Health Organization [WHO], 2015). In 2013, WHO focused on nine global targets to reduce non-communicable disease deaths globally (WHO, 2015). Two of the global targets focused specifically on CVDs by calling for the reduction of hypertension and CVD prevention through drug therapy and risk reduction by education on such topics as increasing exercise, healthy diets, and tobacco cessation (WHO, 2014). Many people diagnosed with CVD eventually will develop heart failure. The number of people diagnosed with heart failure is rising in Canada with an estimated 600,000 Canadians living with heart failure and 50,000 are diagnosed each year (Heart and Stroke Foundation, 2016). The costs associated with heart failure are high as it is a long-term chronic condition that worsens over time leading to long and frequent hospital stays, reduced productivity potential of the individual afflicted, and additional economic social costs to the family and community (Freydberg et al., 2010; Joo et al., 2014; Kitko & Hupcey, 2013).

The Canadian Cardiovascular Society has developed a comprehensive set of

recommendations to assist in the diagnosis and management of heart failure (Arnold et al., 2006; Grady et al., 2000). Patients with heart failure may receive treatment from their primary care provider or through a specialized heart failure clinic [HFC] (i.e., outpatient HFC) or through both as appropriate (Arnold et al., 2008). Outpatient HFCs are interdisciplinary; staffed by physicians, nurses, pharmacists, dieticians, social workers, and other healthcare professionals bringing their respective expertise in heart failure. Heart failure clinics provide patient and caregiver education and may offer other services such as telemanagement or telemonitoring and home visits (Arnold et al., 2006). Registered nurses and nurse practitioners play a major role in combating chronic disease by adapting interventions and selecting supports for each patient that will positively impact his/her health and functional status (Canadian Nurses Association [CNA], 2012).

In January 1999, 11 HFCs were established across Canada to improve the management of heart failure, implement proven therapies, and collaborate in innovative research approaches to optimize patient management (Canadian Heart Failure Network, 2009). Each clinic follows the benchmark guidelines for physician referral to a HFC. The American Heart Association, the American College of Cardiology, and the New York Heart Association established specific guidelines for how long patients with heart failure can wait to be assessed by an HFC from the time of referral (Arnold et al., 2008; Howlett et al., 2016). According to the guidelines, emergent cases are to be seen by a specialist less than 24 hours from time of referral (Appendix A). These emergent cases include patients diagnosed with acute severe myocarditis, cardiogenic shock, transplant and device evaluation of the unstable patient, new onset acute pulmonary edema, and heart failure with acute coronary syndrome or myocardial infarction (Howlett et al.). Urgent cases are to be seen within two weeks of referral by a specialist (Arnold et al.; Howlett et al.). These urgent cases include patients diagnosed with progressive heart failure, those newly

diagnosed with heart failure who are not improving with therapy, patients' progression to New York Heart Association Classification IV, post myocardial infarction heart failure, those with severe heart failure with valvular, renal disease, or hypotension, and/or those readmitted with an exacerbation of heart failure (Howlett et al.) (Appendices A and B). Semi-urgent or intermediate risk cases are to be seen by a specialist less than four weeks after referral and include those who are stable and newly diagnosed with heart failure or those with a New York Heart Classification II/ III or with worsening heart failure on therapy (Howlett et al.) (Appendices A and B). Patients with a New York Heart Association Classification I and New York Heart Association Classification II should be seen within 12 weeks of referral (Howlett et al.) (Appendices A and B).

Patients registered with an HFC receive an individualized plan of care focusing on diagnosis and initiation of medical treatments, such as drug therapy or mechanical interventions, through collaborative efforts from health care professionals and cooperation of the patient and their immediate caregivers (Arnold et al., 2008). This interdisciplinary care includes close follow-up as well as patient and caregiver education on topics such as how to control sodium and fluid intake, how to weigh themselves daily, and how to recognize the signs and symptoms of worsening heart failure. Patients also receive an algorithm to adjust their diuretics, and exercise and psychosocial counseling (Andersson, Eriksson, & Nordgren, 2013; Howlett et al., 2010). Patients may be discharged from a HFC if the patient has remained stable with a New York Heart Classification I or II for six to 12 months, has a measured left ventricular ejection fraction greater than 35%, has responded well to treatment, or has a consistent general physician providing care (Howlett et al., 2016).

For those patients who have access to an HFC, improvements to their health may include

an increase in functional capacity and quality of life, concomitant with a decrease in emergency room visits, hospital readmissions, or length of stay in hospital (Crowder, 2006). Patients with heart failure reported choosing to attend an HFC because of the referral by their physician and continuing to participate in the program due to the positive outcomes, a sense of belonging, and access to health sustaining information (Crowder, 2006). Patients with heart failure who have attended an interdisciplinary HFC recommend early enrollment (ie: at the first signs of symptoms) as they receive cardiac specific education related to diet, medication titration, and self-assessment, which may improve their quality of life (Crowder). Those patients unable to attend an HFC may become vulnerable, physically or psychologically, to the disease process due to the lack of information, education, and support.

In Regina, Saskatchewan, the Congestive HFC is an interdisciplinary clinic staffed by a registered nurse, dietitian, social worker, pharmacists, and five cardiologists. Services offered by the clinic include wellness assessments, pharmacologic therapies, and education. The clinic is open to all patients with heart failure. However the clinic sees patients with a New York Heart Association Classification of II, III or IV (Appendix B). The HFC is not available to patients who have a New York Heart Association Classification of I.

## **1.2 Self-Management Programs**

Self-management programs differ from traditional patient education. Self-management techniques provide patients and families with the tools and resources they need to manage their physical and emotional symptoms (Health Council of Canada, 2012). Self-management strategies are taught in outpatient heart failure clinics and reinforced through the use of telemonitoring and web-based interventions. Patients diagnosed with heart failure receive education focused on learning and practicing necessary skills for self-care physically and

emotionally at home (Powell et al., 2010). Patients and caregivers participate in educational sessions to learn about the importance of medication adherence, steps to take with a sudden weight gain, imperative of sodium and fluid restriction, and need for regular physical activity (Arnold et al., 2008; Powell et al., 2010).

### **1.3 Outpatient Heart Failure Clinic**

Patients with heart failure receive help and support from their primary care provider or a HFC. The majority of patients with heart failure in Canada are treated by their primary care provider as they are familiar with the patients' previous health histories (Arnold et al., 2008). Patients may or may not be referred by their primary care provider for evaluation by a HFC. Referral is recommended for patients with heart failure who have a high risk of readmissions including patients with the previous hospitalization for heart failure, multiple co-morbidities, or those individuals with limited social support (Arnold et al.). Depending on the severity, the patient diagnosed with heart failure may visit the clinic once every one to four weeks or as needed. Appointments may lengthen to once every three to six months for individuals with intermediate risk or to every six to 12 months for low risk individuals (Howlett et al., 2016; Seto et al., 2012). Patients attending the HFC receive information about their clinical diagnosis and may phone the HFC with any questions or concerns. Potential benefits of participation include a reduction in the number of hospital admissions, access to health care professionals as needed, and social support from meeting others with the same condition (Ågren, Evangelista, Davidson & Strömberg, 2013; Whitty et al., 2012). Potential barriers to attending a HFC include lack of transportation and transportation costs that may cause a financial burden to those individuals on a limited income (Whitty et al.).

Care provided by family members and friends help patients with heart failure to identify

early signs of acute illness, encourage appropriate diet and medication use, support lifestyle changes, and assist in understanding complex self-care information (Piette et al., 2008). Howlett et al. (2016) recommend including family members and caregivers in self-care management as caregivers provide substantial support to patients diagnosed with heart failure and need to be considered partners in their overall plan of care. Caregivers want equal access to Web-based information to help their loved ones and to provide better care (Nahm et al., 2008; Piette et al., 2008). When given access to the web-based programs, caregivers reported that the programs were helpful in providing assistance and additional information about heart failure (Piette et al., 2008).

Following the use of a Web-based application, patients with heart failure were found to have an increase in knowledge (Nahm et al., 2008; Strömberg et al., 2006) and an improved quality of life (Westlake et al., 2007). Patients with heart failure ranked signs and symptoms as one of the most important topics for learning. Followed by learning more about heart failure prognosis, risk factors, medications, general information, diet, psychological factors, and physical activity (Boyde et al., 2009b). These findings were supported by Nahm et al. (2008) who found that heart failure patients wanted to have up-to-date information on results of research, medications, and laboratory tests, rather than general information about heart failure. Patients want to verify if they are still following the recommendations as prescribed by their physician (Boyde et al., 2009a) and found it useful to access to this information over long periods (Delgado et al., 2003).

Web-based applications offer different levels of information for each user. Individuals may use a site to learn basic information and then use the same site to find out more in-depth information. These needs may be met through the use of a specific web design structure and



links to external sites (Nahm et al., 2008). However, the evidence suggests that most tools were designed by individual researchers and lacked a common approach. These tools were made available to participants for specific periods of time and specific projects.

#### **1.4 Using Technology in Nursing Practice**

Health 2.0™ is a term that denotes the use of web-based tools by healthcare professionals to communicate with patients, collaborate with other health professionals, and provide health information. In the United States and Canada, many hospitals are actively using social networking platforms as part of their professional communications. As of April 2016, over 1500 hospitals in the United States used YouTube, Facebook, Twitter, and/or LinkedIn to communicate with employees and the public (Mayo Clinic Center for Social Media, 2016). In Canada, 261 hospitals are actively using YouTube, Facebook, or Twitter (Fuller, 2011). Nurses and other health care professionals are using social networking sites for professional purposes such as research, educational tools, information sharing, and networking with other individuals with similar interests.

The term *social networking* refers to web-based and mobile platforms that allow users to create and share conversations with other users or the public. There are two primary types of social networking tools available:

- Sites that focus on communication within existing or created social networks, where information flows within an established group of people who are already known to each other (Berg, 2012). Examples of this kind of social network site include Facebook, Twitter, and NING.
- Sites that expand social contacts as they allow users to make new social connections online. An example of this kind of networking site is LinkedIn, which focuses on

developing professional contacts and networks (Berg, 2012).

#### **1.4.1 Facebook.**

Facebook is a social network site that allows individuals to construct a public profile, to choose other users to share a connection, and to view what other users have posted within the system. After joining Facebook, the user is asked to generate a profile page by answering personal questions respecting age, location, interests, education, and work history, and to upload a profile photo (Boyd & Ellison, 2008). The visibility of profile pages varies according to the privacy settings established by the user; however, profile pictures and limited information may be visible to any individual searching the Internet.

Facebook members are encouraged to find other Facebook users with whom they have a relationship. The term for this type of relationship is "friend." The user finds friends by searching the site according to location, previous employment, or educational history. Alternatively, potential friends may be identified for the user by Facebook itself based on his/her friend's friends. The user is then prompted to add the friend, and the other user may accept or decline the friend invitation. The friends' list is an important part of a social network site (Boyd & Ellison, 2008). Facebook users may browse the friend's list to identify others with whom they have a relationship. Users may leave messages on their friends' profiles by posting comments, or they can send messages privately through webmail or instant messaging (Boyd & Ellison; Sewell, 2016). Also, users may upload photos, live updates, and videos to their Facebook accounts.

Facebook is continually changing and offering new services. Facebook members can choose to prioritize their friends' posts which allows their posts to show first in their newsfeed before advertising. Members can also unfollow their friends so that any new posts do not show up in their newsfeed (Elliott, 2016). A new feature allows the Facebook member to post a

question or status update without it remaining in their timeline. This feature will allow hospitals to promote special activities to their members without the update remaining on the site. Other features include a historical look at what happened on this day in history, which looks back at any time in a member's history on Facebook (Facebook, 2016). The messenger app allows members to communicate with their friends through text messages, emojis, or videos. Emojis are pictorial representations of feelings, places, activities, and objects. The emojis are popularly used in text messages to convey messages such as being happy, sad, shocked, or angry.

#### **1.4.2 Twitter.**

Twitter is a social network application and micro-blogging service that allows users to connect and interact with each other through short messages or “tweets.” A tweet is a message posted on Twitter that contains up to 140 characters (Twitter, 2016a; Sewell, 2016). After setting up an account, users create a profile to share information about themselves with others. Once the profile is created, the user may start sending tweets or search for other users to follow (Twitter, 2016a). Tweets include a hashtag, a # symbol, before a relevant word or phrase to categorize their tweets and to make them more searchable on Twitter (Twitter, 2016b; Ventola, 2014). Individuals who wish to receive a user's tweets become "followers." The list of followers is displayed by profile picture and name and can easily be browsed by the general public who may or may not have a Twitter account. There have been several innovations to Twitter to make it more user friendly and extend its applications. For example, when a user replies to a tweet, the @name does not count in the 140 characters which, allow the user more words in the conversation. As well the use of media in the form of photos, videos, or polls do not count towards the 140 characters (Sherman, 2016). Currently, 967 hospitals in the United States are using Twitter in a variety of ways, such as sending specific reminders to patients to take

medications, track side effects, or make a follow-up appointment (Seil Kim, 2012). Physicians have used Twitter to share clinical data presentations and their perspectives on the treatment (Chaudhry, Glodé, Gillman, & Miller, 2012).

### **1.4.3 YouTube.**

YouTube is a video-sharing site that allows users to upload videos for public viewing. After uploading a video, the public may comment or rate the video by giving a “thumbs up” or “thumbs down” rating. In the United States, 719 hospitals use YouTube (Mayo Clinic Center for Social Media, 2016). There are many nursing and health care-related videos available to view on topics such as the image of nursing, discussion of work life in different hospital units, types of surgical procedures, and descriptions of services available at various hospitals (Jung, Hur, Jung, & Kim, 2015).

Social networking sites gaining popularity in healthcare include LinkedIn, NING, and Pinterest. LinkedIn focuses on developing a professional network. Users create a profile that highlights their educational and work-related experiences for networking. Users are encouraged to make a connection with others. Employers may list jobs on the site and search for potential candidates if the user has uploaded a resume (Sewell, 2016). In the United States, 656 hospitals are actively using this service (Mayo Clinic Center for Social Media, 2016). NING allows users to create networks on specific topics by focusing on user-generated content, as members can share photos and videos, ask questions, and make comments on networks to which they belong. The user who established the network can choose to make the site available to the public or secure access by inviting others to join the network. Several NING sites focus on a particular health care issue or disease process. Pinterest focuses on using images as a medium to express personal preferences to others. Users upload pictures to a particular bulletin board or pin a link to

a website or blog (Pinterest, 2016). Pinterest is quickly gaining the attention of health care professionals as users may post pictures or cartoons on health-related topics. All these social networking sites share a common set of rules. Users connect and interact with other users who are part of their extended network or with strangers with whom they share common interests. After signing up for an account, the user becomes legally responsible for the information posted. It is important to note that social networking sites are continually evolving, so users are cautioned to stay abreast of changes, especially any changes in privacy rules.

Health care adoption of social media is still in its early years. The use of social networking allows health care professionals to connect with patients and other experts in a specific field (Sewell, 2016). However, this kind of social communication was not specifically designed for use in health care settings. It is important to consider the legal and ethical obstacles that need to be overcome in order to successfully apply these tools (Canadian Nurses Protective Society [CNPS], 2012; Sewell, 2016). Nurses and other health care professionals must take into consideration the risks and responsibilities involved in incorporating social media into practice. Social networking technology must be used appropriately, respectfully, and safely. Information made available through social networking activities must be accurate and help patients and their families navigate through misleading or contradictory information to make informed medical decisions, protect the privacy and confidentiality of patients and others, and safeguard access to health information for social media users and non-users alike (CNPS).

Several ethical and legal considerations need to be taken by healthcare professionals when using the Internet and social networking tools. Registered nurses follow the CNA's Code of Ethics for Registered Nurses (2008) which provides an overview of the values and commitments nurses make to patients in all contexts and domains of nursing practice. Registered nurses

"respect the right of people to have control over the collection, use, access, and disclosure of information" (CNA, 2008, p. 15). Health care organizations are required to follow federal and provincial legislation that legally protects an individual's right to privacy and confidentiality of personal and health information (Sewell, 2016). In Saskatchewan, the Health Information Protection Act (HIPA) emphasizes the protection of electronic health information, along with the individual's right to consent to the use of personal information relating to mental or physical health (Government of Saskatchewan, 2003). A breach of confidentiality may inadvertently occur when posting comments, pictures, or videos that may contain sufficient detail to identify a patient (Fraser, 2011; National Council of State Boards of Nursing [NCBSN], 2011). Nurses must not transmit electronically any images related to their patients or patient care (NCBSN), and they must not name or publish information that may lead to the identification of a patient in their care. Health care professionals need to realize that posting anonymously or under a pseudonym does not protect the user against a breach of confidentiality or defamation of character (CNPS, 2012). Nurses need to respect and reinforce professional boundaries as becoming a "friend" and communicating on a social networking site may extend their professional liability if offering health information or advice when responding to a question or comment posted on a social media site (CNPS; Fraser; Ventola, 2014). Nurses using social media professionally must be aware that advising patients on a particular course of action online may breach confidentiality and professional ethics.

### **1. 5 Online site: NING**

NING is an online service that allows users to create their social network (NING, 2016). The social network becomes a community where others members can join by either searching for the community on a search engine or by invitation. A moderator customizes NING to control

specific areas such as membership and postings (NING). NING provides tabs at the top of the screen which provide easy access to features such as photos, videos, blog posts, groups, and forum postings. All members on the site may add photos, videos, and postings to the blog, group, or forum pages (Living Well with Heart Failure, 2015). The latest activity by members is posted to the site so that other users can review to see if there is a particular posting that they would like to view. Members may post a picture of themselves on their profile along with other personal information such as gender or place of residence. Members can send private emails to each other by clicking on the name of the individual member (Living Well with Heart Failure). Members are invited to join the group free of charge. To access the NING site, members are required to have access to a computer and an Internet connection available through a library, home, or on a mobile phone.

## **1.6 Literature Review**

### **1.6.1 Literature search.**

Social networking sites such as Twitter, Facebook, YouTube, blogs, and social websites utilize web-based and mobile platforms that invite and enable individuals with common interests to come together "virtually" to share experiences, ask questions, and provide emotional support. A literature review was conducted to explore the effectiveness and potential of using social networking as a source of social support for elderly patients. An initial search of nursing and health care literature was conducted on CINAHL™, Medline, PubMed, Web of Science and Embase between January 2010 and October 2012. An ongoing review of the literature was conducted until June 2016. Search terms included *cardiology*, *collaborative decision making*, *community informatics*, *decision making*, *computer assisted*, *communities of practice*, *e-caregiver*, *e-health*, *electronic communities*, *health information networks*, *heart failure*, *m-*

*health, networked societies, social networks, social technologies, social capital, support-psychological, and /or virtual communities.* To further locate relevant articles, some reference lists of selected research articles were reviewed. Research articles were included if written in English, focused on social networking in health care in general, social networking with elderly patients, or social networking with heart failure patients. Research articles were excluded if they were not available at the time of writing or if they examined social networking for a health condition other than heart failure such as weight loss, exercise, or smoking cessation as these articles tended to focus on a younger population which may use social networking routinely. In total, 19 articles were available at the time of writing the proposal. These articles were obtained through a manual search of the Health Sciences Library at the University of Saskatchewan and accessed through interlibrary loans.

#### **1.6.2 Review of the literature.**

Social networking is seen as a low-cost option for increasing communication between patients and health professionals (Martin, 2012; Neiger et al., 2012). It is an effective means to reduce disparities as social media tools increase access to primary medical care (Godfrey & Johnson, 2009; Martin; Neiger et al.; Villagran , 2011); however, age, race, socioeconomic status, or educational disparities may impede a patient's ability to use web-based interventions due to lack of access (Green et al., 2011; Vassilev et al., 2011; Weaver et al., 2009). Social networking can eliminate unnecessary visits to a health care professional as patients can use web-based tools in their home to communicate with these professionals (Villagran). Elderly people, who are members of online communities, participate because they want to be heard and to share information (Godfrey & Johnson; Karahasanovic et al., 2009). Seniors are very interested in the co-creation of information (Godfrey & Johnson; Karahasanovic et al.; Xie,



Watkins, Golbeck, & Huang, 2012,) and the usability of the sites is critical (Karahasanovic et al.; Schneider, van Osch, & de Vries, 2012; Whittaker, 2012). Seniors would like to have their own social space that they can discuss private matters and share content only with specific members of the group (Godfrey & Johnson; Karahasanovic et al.), as privacy is a concern (Fisher & Clayton, 2012; Karahasanovic et al.; Whittaker; Xie, Watkins, Golbeck, & Huang). Seniors share their own experiences and discuss current health conditions that affect ability to engage in self-management practices (Eysenbach, Powell, Englesakis, Rizo & Stern, 2004; Nahm, Resnick, DeGrazia & Brotemarkle, 2009; Vassilev et al.; Weaver et al.) and feedback from others can serve as positive reinforcement for health behaviors (Poirer & Cobb, 2012; Schneider, van Osch, & de Vries). The most popular choice for communication among this age group is email (Bashi, 2012; Fisher & Clayton; Xie, Watkins, Golbeck, & Huang, 2012) and individuals are motivated to use social networking when initiated by others sending messages (Nahm et al.; Karahasanovic et al.; Poirer & Cobb). A health care professional needs to serve as a moderator to ensure the accuracy of health information posted (Nahm et al.).

### **1.6.3 Gaps in the current level of research.**

One of the limitations of the extant research is that the majority of studies focus on adults over the 18 years, so the results may not be generalizable to adults over 50 years. Another limitation is that many study samples include older adults, with little or no experience using the Internet, in online support groups. The prospective population for persons living with heart failure are baby boomers. Additional research is needed on types of social networking tools and barriers to their use for this target population with respect to the baby boomer generation's experience using the Internet, their requirements for disease specific resources, and what they view as a supportive environment. Researchers need to develop the next generation of social

networking tools with the individuals who will be using the tools. Research should focus on the use of Health 2.0 tools that focus on collaboration, openness, participation and social networking on specific disease processes. Future research should explore the properties of social networking sites focusing on health care; why some people join social networking sites, while others do not; and the preferred type of support received online such as emotional, tangible, or informational.

### **1.7 Online Social Support Theory**

The theory of online social support was developed by LaCoursiere (2001) to assist in the conceptualization of online social support and to provide a theoretical framework for research. This theory was used in framing this research study. The theory of online social support (LaCoursiere) includes all aspects of the nursing metaparadigm. Health is a dynamic process that fluctuates over time with changes in the disease process. The person is using web-based tools for social support. Nursing includes the "thoughts and behaviors of the nurse who engages in online social support activities" (LaCoursiere, p. 65) and the environment is supportive and virtual. The theory of online social support was developed to describe the process of support characterized by interpersonal relationships between others who are generally unknown to each other over the Internet (LaCoursiere) (Appendix C).

Two focal concepts of the theory of online social support include online social support and linking. The person seeks online social support when there is a change in health or perceived health status that may be either acute or chronic in nature. Mediating factors are health, demographics, Internet use, and perceived individual factors (LaCoursiere). These factors result in support-seeking behaviors.

Social support is viewed at a group level with an infinite number of ways that support can occur between patients, caregivers and nurses. Multiple transactions lead to relevancy

development and need differentiation. All of the information gained through electronic support interchanges are processed and evaluated for personal relevancy. The person determines which interactions have personal meaning and then can determine if they would like additional information on a particular topic from another person. After repeated interactions the person continues to return to the online group with a belief in the power of online social support and shares information learned with others (LaCoursiere, 2001). Linking is the final outcome of the theory. It is defined as "the conscious and/or unconscious process of relating and weaving emerging awarenesses to previously learned thoughts or information" (LaCoursiere, p. 67). Linking is a process where the person integrates and assimilates relevant online social support experiences. From these insights, the individual develops his/her own "web" of personal health information in order to successfully navigate between sites in pursuit of the health information and supports.

### **1.8 Personal Interest in this Area of Research**

As a registered nurse, I have had the opportunity to work with many cardiology patients who are admitted to the hospital and stay for lengthy periods of time. My personal interest lies with the topic of chronic diseases and the utility of social networking tools to improve access to information for anyone personally affected by a chronic illness. Sixteen years ago, I was diagnosed with multiple sclerosis and understand the day-to-day challenges both physically and socially when living with a chronic potentially debilitating disease. Health 2.0 tools allow patients and caregivers quick access to information and others diagnosed with a chronic illness. I would like to ensure this information and shared experiences are safe and accurate. In my personal experience using the Internet to seek health information I have found misleading and nonfactual information on sites. As an individual diagnosed with a chronic disabling condition, it

is important to be able to access accurate information whenever it is needed, night or day. For example, I like to be able to find out if the symptoms that I am dealing with are common and easily managed at home or if I need to consult a specialist by doing a quick search on the Internet and by finding someone with whom I share a similar health story. It is also important to be able to explore various treatments and side effects for my own peace of mind when learning to live with a new medication or treatment regimen. This peace of mind may come from the Internet when a physician's office is closed. My interest in the use of social networking began years ago as I saw how health care professionals used Health 2.0 tools in incredible ways. I am interested in developing an online community where health care professionals, patients, and caregivers can share ideas, find support, and discover new ways to work together. As a nurse, I am interested in creating online content that can reach wider audiences than traditional methods such as teaching at the bedside or in a clinic, while keeping professionally current with the medical literature.

### **1.9 Significance of the Study**

Following a Google search, nine heart failure online bulletin boards were identified serving as a form of support for the patients, families, and friends. It is noted that other support groups focusing on CVD were listed, but many of these involve classes or in-person participation. These online communities (i.e. bulletin boards) were established as a way for those affected by heart failure to share stories and ask questions. These sites were currently active with recent posts and recipe suggestions.

The researcher designed, created, and developed the Saskatchewan Heart Failure Network and Living Well with Heart Failure NING sites based what the researcher viewed as the best model of online communities. The Living Well with Heart Failure NING site provided an online environment for caregivers to share information with each other on a site moderated by

the researcher who has previously worked on cardiology units. The significance of this research study was that it extended knowledge around the use of social networking for caregiver information and support. By incorporating the theory of online social support and focusing on caregivers, the research study provided a greater insight into when caregivers seek online information and support. The results of this study uncovered critical information related to the development and moderation of a health care professional and caregiver social networking site.

### **1.10 Research Purpose**

The purpose of this interpretive description study was to explore the factors that have and will continue to influence or contribute to caregivers' use of social networking as a form of social support when a family is learning to live well with heart failure. Ultimately, the long-term objective is to enhance an originally created social networking site developed by the researcher of this study for caregivers and patients diagnosed with heart failure to use provincially and nationally. The following questions guided this interpretive description research study: How do family members and/or nonfamily supporters of patients with heart failure define the illness, their day-to-day situation, and social support? How do professional health care professionals define social support for caregivers of patients with heart failure? How do family members and nonfamily members manage their lives and the lives of their loved ones? Under which conditions do family member and nonfamily members of patients with heart failure use social media as a source of health information and peer support? What do family members and nonfamily members for patients with heart failure see as the consequences of using or not using online sources for information and support? What do professional health care professionals consider to be the consequences of using or not using online sources of information and support for caregivers? The results of this research study provide insights into factors that contribute to the

caregivers' utilization and uptake of online sources of health information and peer support and identify caregivers' and health care professionals' perceived consequences of utilizing online resources and social support.

### **1.11 Organization of the Study**

Chapter 1 presented the introduction, review of related literature and research related to heart failure management, education, and social support, statement of the problem, research questions, significance of the study, definition of terms, and limitations of the study. Chapter 2 contains the methodology and procedures used to gather data for the study. Chapter 3 presents the results of analyses to emerge from the research study. Then a discussion of the findings will be reported in Chapter 4. Chapter 5 contains implications for nurses, health care professionals, caregivers, web developers and nurse educators along with recommendations for further research.

## **CHAPTER TWO**

### **Research Methodology**

#### **2.1 Research Design**

In this qualitative study, an interpretive description approach of an emerging experiential phenomenon was undertaken. Interpretive description is a noncategorical qualitative methodology developed by Drs. Thorne, Reimer- Kirkham, and MacDonald-Emes in response to the need for knowledge generation in the applied health disciplines (Thorne, 2008). The interpretive description approach was developed to generate a better understanding of complex experiential clinical phenomena within their respective fields (Thorne). Interpretive description is influenced by other more traditional qualitative methodologies including ethnography, phenomenology, and grounded theory.

Interpretive description adopts a constructivist and naturalistic orientation to research. This approach assumes that absolute, objective knowledge is unattainable as reality is socially and experientially based on the persons involved in the situation (Hunt, 2009). The human health and illness experience is influenced by complex interactions between psychological and biological phenomena. In such circumstances, registered nurses apply their practice knowledge to a particular situation which results in shared realities between the health care professional and individual. Interpretive description contributes to "our understanding of how people experience their health and illness and what nursing can do to make a difference" (Thorne, Kirkham, & MacDonald-Emes, 1997, p. 173). The research examines a clinical phenomenon with the goal of identifying themes and patterns, while exploring variations among individuals (Hunt, 2009).

## **2. 2 Ethical Considerations**

Ethics approval was sought and obtained through a harmonized provincial review process for the multi-jurisdictional application from the Behavioral Research Ethics Board at the University of Saskatchewan and University of Regina, and from the Regina Qu'Appelle Health Region Research Ethics Board. Following approval, posters requesting participation by health care professionals and caregivers were posted in several key areas in nursing units specializing in heart failure in both hospitals within the health region as approved by the Director of Cardiosciences in the Health Region (Appendices D and E). Participants interested in the study contacted the researcher by phone or email. Following this initial expression of interest, the researcher set up a time to meet up with each participant to provide more information on the research study. The researcher met with each health professional individually who volunteered to participate in the study to review the intent of the research project, to answer any questions, to discuss the focus group process, and to obtain an informed signed consent. All health care professionals received a signed copy of the consent for their records (Appendix F). The researcher also set up a time to meet up with each caregiver individually who volunteered to be part of the study. All meetings were set up for a time and location of the potential participant's choice. At the meeting, the researcher reviewed the intents of the research project, explained the consent form, answered any questions the potential participant may have had and discussed the website postings and interview process prior to consent being obtained (Appendix G). Informed consent was obtained from the caregivers who volunteered to be part of the study. All engaged caregivers received a signed copy of the consent for their records.

A revised ethics application was submitted for review through the harmonized provincial review process approximately six months after the study was initiated to increase the number of



hospital units and community locations. After the amended ethics approval had been obtained, research posters were placed on various medical units in the Health Region where medical patients, previously diagnosed with heart failure, might be admitted. It was anticipated that increasing the number of medical units, would increase awareness of the project and increase the number of caregiver participants. Research posters requesting caregiver participation were also placed in community settings frequented by caregivers and individuals previously diagnosed with heart disease such as cardiac rehabilitation exercise programs (Appendix E). At this same time, the original research ethics application was amended to include the previous caregivers potentially in a two-part study on the website, with a focus on a caregiver led NING forum, then focusing on a healthcare professional lead NING website forum (Appendix H).

All participants were over 18 years of age. Research procedures minimized fatigue or stress as participants were able to access the Saskatchewan Heart Failure Network NING website or the Living Well with Heart Failure NING site at their convenience. Focus group sessions for the health care professionals and interviews for the caregivers were scheduled to best suit their individual schedules. All efforts were made to ensure confidentiality of all participants. To maintain confidentiality, two NING websites were set up. Health care professionals accessed the Saskatchewan Heart Failure Network NING website, and the caregivers accessed the Living Well with Heart Failure NING website. The membership for each site was restricted to the researcher and applicable participant groups, with unique sites for professionals and caregivers (i.e. neither could access the other group's site). This limited access was to ensure confidentiality and to encourage a more open dialogue.

Security settings for the NING websites were set for membership to be available by invitation only. Health care professionals and caregivers were provided with a free email account

to use throughout the study period for added protection of their identity. The NING website required participants to provide their name, email address, and other identifying information to the webmaster. To maintain confidentiality, each account was set up by the researcher using the free email address, a unique username, and password for each participant. The researcher also set up each account with no additional identifying information such as birthdate, location, and sex. The researcher then emailed the information on how to access the website to each participant by using their free email account. The health care professional or caregiver could then reset the password associated with their individual account if they choose to do this. The researcher limited the profile questions for new members to ensure confidentiality of the health care professionals and caregivers. Both health care professionals and the caregivers did not have the option to add a photograph or provide age or birth date to their profile. A default picture for NING was used for all health care professionals. Profile images for the caregivers consisted of heart icons in various colors chosen by the researcher per the caregivers' requests. A pseudonym was used to identify the health care professionals and caregivers. NING also requires the location on the user profile; all places were identified as the province or city in which the research study was conducted. All caregivers, except two, requested that the researcher choose their pseudonym. Pseudonyms were chosen according to the most popular baby name in the year they were born. Only the researcher had access to the name, pseudonym, email address, and demographic information for each participant. All linkable personal information, has been stored in a secured private office in a locked filing cabinet at the University of Saskatchewan.

### **2.2.1 Healthcare professionals.**

There was some risk to health care professionals who volunteered to be part of the research project as they were known to each other. To mitigate the risk, each health care

professional was asked to keep all discussions private. The researcher took steps to safeguard confidentiality by not informing the health care professional who the other health care participants were before the focus groups sessions or the identity of the caregiver participants. Healthcare professionals were instructed to respect the confidentiality of the other members of the group by not disclosing the contents of the discussion outside the group.

### **2.2.2 Caregivers.**

Caregivers used a pseudonym in the online postings and did not post any identifying information on the site. All comments to other participants were very supportive with discussions reminiscent of conversations between individuals in a waiting room of a clinic or doctor's office. Steps were taken to moderate postings on the site. All postings were approved by the moderator before accessible on the website by other caregivers. There were no instances of any questionable material or possible violations of confidentiality by the caregivers at any time during the research study. Caregivers and family members continued to receive support, education, and medical care from their primary care provider and/or the HFC in the Health Region.

The Living Well with Heart Failure NING website was intended to provide a forum for health information in which caregivers could share information, stories, and tips about living well with heart failure. When caregivers accessed the Living Well with Heart Failure NING website, a tab notifying the caregivers that the site was not intended to provide all information about heart failure. Each caregiver was advised to seek the advice of a health professional related to any change in health status. Each caregiver signed a waiver of liability stating that they were aware that the researcher was not responsible for medical information posted by the members on the social networking site (Appendix I). Each caregiver was directed to contact their primary

care provider, or the HFC, or seek emergency treatment at the nearest hospital immediately if they had any questions or concerns about their health or well-being, or that of a family member/friend, including medical condition, treatment plan or a change in treatment plan.

There was a potential risk that specific information could be attributed to a participant as caregivers continued to receive treatment from the HFC in the Health Region. Caregivers were reminded not to share information about their participation in the research study such as sharing their pseudonym with others or their age, gender, diagnosis, or identifying information on the site. The researcher moderated content postings, and postings were not available for viewing until approved by the researcher. The researcher monitored for identifiable information such as names, dates, or locations. The caregivers provided no identifiable information, however, if any identifiable information had been presented, the post would not have been made available for viewing. The interview questions focused on the caregiver's views on social support and were not intended to embarrass, humiliate, or cause grief for the caregiver. Caregivers were able to withdraw from the study at any time with no consequences to the services received through the HFC or Health Region. Two caregivers participated in the initial interview and NING website postings but did not complete the final interview due to personal circumstances. These two caregivers did not withdraw from the study formally but chose not to participate in the final interview. All caregivers were aware that the information posted would remain visible on the site to members only.

### **2.3 Development of the Saskatchewan Heart Failure Network**

The Saskatchewan Health Care Network NING site was developed early on in the research study while the researcher was taking an elective in social media and open education (Appendix J). The researcher chose NING as the social networking tool due to familiarity with

the online service and the privacy policy. The site was developed using current literature when choosing the color, design and font of the website (Boyde et al., 2009b; Boyde, Turner, Thompson, & Stewart, 2011) as well as the topics taught to new patients admitted to the HFC (B. Hiebert, October, 2011). The developed Saskatchewan Heart Failure Network was presented to the health care professionals for review and feedback (Appendices J and L).

## **2.4 Study Participants**

This study focused on health care professionals and caregivers who were involved with the HFC, a community rehabilitation clinic, or an acute in-patient medical cardiology unit at one of two hospitals located in an urban center. In January 2015, posters requesting participation in the research study were placed in two cardiology units, one step-down unit, two critical care units, two medical units, and one cardiac rehabilitation centre in the Health Region. Posters requesting participation were posted in areas frequented by the healthcare professionals on each of the above units. Posters for caregivers were placed near patient teaching handouts and other care information on each of the units. The researcher regularly ensured that the poster was still available for viewing and replaced any missing poster as required (Appendices D and E).

### **2.4.1 Healthcare professionals.**

In January 2015, health care professionals began to reply for the request to participation in the research study. In total, seven health care professionals responded over a three month period. The healthcare professionals who volunteered to participate in the research study were employed by the Health Region and routinely worked with patients diagnosed with heart failure. All health care professionals were accepted and contacted for their response. The researcher requested possible dates and times that were suitable for their schedule to meet to review the

intent of the study and obtain consent (Appendix F). One of the health care respondents declined participation after signing the consent due to a job change resulting in no further contact with heart failure patients. The health care professionals represented those professionals who regularly teach patients with heart failure topics such as diet, exercise, medications, and available treatments. In total, four of the health care professionals were able to attend the first focus group session. One health professional participant was not able to attend due to her shift schedule. The other healthcare professional was unable to attend due to a medical situation. Both of these latter healthcare professionals provided feedback by email to the researcher based on their review of the Saskatchewan Heart Failure Network NING website (Appendix J).

The first focus group session with the health care professionals was conducted in April 2015. The focus group session lasted approximately 45 minutes (Appendix K). The research was not disruptive for the participants as the focus group session took place during an available time for the participants in the workday with the exception of two participants previously described. The focus group session took place in a meeting room away from the HFC. The healthcare professionals had the opportunity to view the questions immediately prior to the start of the focus group session; however the health care professionals did not receive a list of the questions prior to the scheduled focus group session in order to prepare for the session. All the questions followed the interview guide and participants' comments.

The final focus group session occurring in December 2015 reviewed how caregivers used the website. One focus group session lasted approximately 50 minutes, and two focus group sessions lasted about 35 minutes each. In total, four healthcare professionals attended all three sessions. Two health care professionals were not in attendance due to a change in employment or work status. The researcher reviewed activity on the Living Well with Heart Failure NING site,

provided screen shots of the website as seen by the participants (Appendix N) and asked probing questions according to the interview guide (Appendix M). All focus groups sessions were electronically taped and transcribed verbatim. The transcripts and electronic recordings are being stored in a locked cupboard by the researcher at the University of Saskatchewan where they will remain for at least seven years from the completion of the study (2016-2023).

#### **2.4.2 Caregivers.**

In May 2015, caregivers began to reply to the request for participation in the research study. Caregivers were identified as family or friends that routinely assist the patient on a daily basis with any aspects of their care. By August 2015, 11 caregivers had responded with interest in participating in the research study. All respondents were contacted and thanked for their response and asked about dates and times that would be suitable to review the consent form, the website, and conduct the initial interviews. Five of the eleven respondents declined to participate due to personal reasons. Two caregivers were admitted to hospital for personal medical reasons so declined to participate in the research study due to study timing, and three caregivers did not respond to the request to meet with the researcher. In total, six caregivers participated in the research project.

Current literature and research on the subject were reviewed as another source of data. The literature review continued during the data collection and analysis phase in order to find any additional research on the concepts revealed during the coding process. Terms included *cardiology, collaborative decision making, community informatics, decision making, computer assisted, communities of practice, e-caregiver, ehealth, electronic communities, e-patient, health information networks, heart failure, mhealth, networked societies, social networks, social technologies, social capital, support-psychological, and /or virtual communities* in varying

combinations to locate empirical research.

## **2.5 Instruments and Procedures**

### **2.5.1 Data Collection.**

**2.5.1.1 Healthcare professionals.** Data collection began with the individuals who had experience with assisting others to live well with heart failure and with those that had personal experience living with heart failure. Data collection involved the purposive selection of research participants, along with collateral data sources, such as lay print, media information, case reports, and clinical papers. These materials were chosen by a Google search using term such as social media, social networking, caregivers, and heart failure. Prior to data collection, the health care professionals who volunteered to be part of the study and who signed the consent were provided with a newly created free email address and pseudonym to access the site. This preview allowed the health care professionals to view the website, how it would appear for the members, the type of information provided, the forum questions, the postings, the groups, along with additional links and resources. Each health care professional had access to the Saskatchewan Heart Failure for Network NING website for 20 days before the focus group session.

Data collection was conducted using open-ended interview techniques that allowed participants to respond to questions in their words during a focus group session or a face-to-face interview. Interview questions were guided by the major research questions for the study (Appendix K). Questions focused on how interested the health care professionals were with a website that helped people to manage their health. Health care professionals were asked questions about their perceptions on the frequency of Internet usage by caregivers when seeking health information and the types of information that is important to include on the social



networking site. Healthcare professionals were asked to reflect on the consequences of using or not using online sources for information and support by critiquing the Saskatchewan Heart Failure Network. Healthcare professionals also reflected on the information provided on the website to determine readability of the information, the benefits and risks to using the site, and if they would recommend the website to patients and caregivers or if they would discourage its use. Following this session, feedback provided by the health care professionals was used to develop the caregiver website Living Well with Heart Failure NING (Appendix L).

A second focus group session was conducted after the caregivers used the Living Well with Heart Failure NING site. During this session, health care professionals were shown non-identifiable screen shots of the discussions on the site and asked for their opinion on the effectiveness of social support (Appendix L). Interview questions followed the interview guide and participants were asked what parts of the site did they think was most useful? Not useful? If there were any benefits to participation? Suggestions for improvement? And if they would recommend the use of social networking to their clients?

#### ***2.5.1.2 Caregivers.***

Data collection was conducted at the initial meeting after obtaining informed consent. The purpose and objectives of the project were explained to each participant before obtaining consent. If the caregiver agreed to participate in the research study, the consent form was signed (Appendix G) along with a waiver acknowledging that the caregiver would seek medical attention with any change in medical condition for their family member (Appendix I). The researcher conducted the interview using open-ended interview techniques that allowed participants to respond to questions in their words during two face-to-face interviews. Concurrently, a series of concept maps were developed by the researcher to gather information

about the caregiver and patient problems and to reflect upon how to solve them (Schuster, 2000). The concept maps were developed based on the clinical data collected by talking with the caregivers. Each concept map (Appendix M) was prepared with the major medical diagnosis in the middle of the paper with nursing diagnoses flowing outward. The nursing diagnoses are actual problems based on assessments (Schuster). The concept maps were used to remain attentive to the issues around care and heart failure experienced by the caregiver but also to identify commonalities among the caregivers' experiences.

The first interview was scheduled after obtaining informed consent and before the caregivers accessed the Living Well with Heart Failure NING site. A second interview was scheduled following their participation on the website. Caregivers were given access to the Living Well with Heart Failure NING site and had the opportunity to add videos, blog topics, answer postings, or forum postings. Caregivers chose to answer forum postings or postings from other members. All additions were monitored and approved before posting by the researcher. Tabs allowed easy access to content such as membership rules.

Interviews varied in length from 10 minutes to 45 minutes. Interview questions were guided by the major research questions for the study (Appendix N). Caregivers were asked to define the illness, their situation, social support and use of social media, and their perceived sources of social support. Other questions focused on how often they looked for health related information online, and if the frequency of looking for information had changed. Caregivers also were asked how interested are they in a website that helps people to manage their health, and if they had any favorite websites that they commonly used. To explore any consequences of using or not using online resources, questions were asked respecting what parts of the NING site were most useful, what parts were not useful, and if they received any benefit from using the website

such as an improvement to health behaviors. Caregivers were also asked if they would recommend this website to others (Appendices N and O). Caregivers were invited to participate on a social media site a minimum of 10 times with other caregivers by posting questions and/or replying to other caregivers' postings. The information posted by the caregiver was reviewed as part of the data capture for this research.

Due to issues around recruitment such as the small number of caregivers and minimal depth of input, the researcher submitted a second amendment to the previous ethics application. The six caregivers were to be invited to participate in the second iteration of the social networking site. The second site was to include a focused healthcare provider component such as including a new video or hint of the week from a health care professional instead of solely a caregiver focus. Caregivers continued to use their previous pseudonym and free email address previously provided to access the site. The site used the same information already used; however, in this iteration, the health care professional would take a more active role in participating by sharing health information topics, articles or health videos with the group. A second consent was required for the second iteration (Appendix H). Due to low participation in the Living Well with Heart Failure NING website and after discussion with my supervisor, it was decided that the caregivers would be notified that new content would be made available on the site on a specific date. Three topics were chosen and included advancing information on the subjects of nutrition by adding nutritional information for restaurants and heart healthy recipes for breakfast, lunch, supper, snacks, appetizers, and vegetable dishes. A second posting was developed on exercise and heart healthy choices for increasing activity. A discussion was encouraged by asking caregivers their favorite activities. A final topic on living well as a caregiver was added and focused on self-care by sharing their feelings with a friend, following a healthy diet, and

exercising for themselves, and taking up an activity they enjoyed. These topics were chosen as they generated the most interest on the board or in the first interview session. These discussion postings were placed on the discussion board on the agreed upon times, caregivers were notified of the new discussions one week in advance and were notified that the website would remain active for two weeks following the posting for any discussion. Despite this attempt, caregivers did not respond to the researcher's new discussion postings or place any additional messages on the discussion boards.

### ***2.5.1.3 Journaling.***

Journaling or tracking reflections was conducted throughout the research project. The researcher reflected upon her beliefs about social networking, living with a chronic disease, and ideas about education and nursing practice. Journaling was started early in the research study and was continued through the data collection and data analysis stages. By reflecting on living with a chronic disease myself along with my health experiences that occurred during the research study which required the need for hospitalization and surgery, it allowed me to reflect on my hospitalization and how this may impact my personal beliefs and inductive analysis. A field notebook was kept which documented happenings that were occurring during the research study such as a change in unit management, a change in patient care on the unit from a coronary care unit to a medical intensive care unit. These changes were important considerations in the research study in order to understand possible reasons for the low recruitment of caregivers. This information was kept both in a written journal and electronically as questions and evolving interpretations of the data emerged.

All interviews were electronically recorded and transcribed verbatim. Memos were kept on the changes made to the site throughout the study such as the change in website name. Memos

were also kept on the participant's non-verbal communication during the interview to provide additional information on how the questions were perceived and answered by the participants. Operational notes were kept on the interviews focusing on other questions to be asked based on the interviews, website usage, and current literature. Summary memos were kept to provide an overview of several notes.

## **2.6 Data analysis**

In interpretive description, data analysis involves repeated immersion in the data before coding begins (Thorne et al., 1997). It is based on the processes of synthesizing, theorizing, and recontextualizing data. The researcher alternately becomes immersed in the field followed by periods of immersion in the data. This iterative process allows for refining the inquiry, testing developing conceptualizations, and challenging the abstractions that emerge with theoretical sampling (Thorne et al.). The researcher comes to know individual cases intimately; then relevant common themes emerge that are applied back to specific cases (Thorne et al.). The constant comparison approach was used to develop and refine relevant categories. This method involves comparing different views of the health care professionals and caregivers, as well as by comparing their individual situations, actions, and experiences in order to see what common themes emerge. Then it is important to look back to the individual case to see how that relates to the previous data (Strauss & Corbin, 1998).

In the constant comparison approach, the data from the second interview was coded with the coding from the first interview in mind, and then the third interview was coded by comparing the previous data and so forth (Strauss & Corbin). This procedure is highly focused and begins with first word of the quotation. The researcher asks and reflects upon the word and its meaning (Strauss & Corbin). Along with looking at the meaning of the words, it is important to look at the

properties and dimensions. Properties are specific characteristics of the concept derived from the data. By reflecting on the categories and phenomena then a picture emerges of what is most important issues, concern or matter to the caregivers and health care professionals who participated in the research study. The names of the concepts are chosen by what is the most logical description of what is going on. Examples of the concepts used were *ease of use*, *just Google it*, *travel*, and *provincial only*. The chosen names reflected what was discussed by the health care professionals and caregivers. As concepts were developed, categories emerged which grouped concepts together.

The categories were then derived from the data. Data was constantly compared to previous data so that common categories could be condensed. For example, concepts such as the need for online information and more information required were grouped together. A line by line comparison was conducted to pick up any variation in the data in order to look for some internal consistency within the data from each individual on what they contributed either through posting or focus group/interview contributions. Selective coding was done in which one category was chosen as the core that emerged with the highest frequency as indicators were pointing to this concept and other categories related to it (Strauss & Corbin).

A qualitative data analysis software was utilized was used to aid in the process. NVivo 11™ is a computer-based program that allows the researcher to keep all interviews and other information together in an organized manner. It allows for data such as interview content, to be imported into the program. Then the researcher can begin the process of coding each interview. Although the program does not do the coding for the researcher, it assists the researcher in organizing the coding of each data element and in managing tools such as memos.

## **2.7 Rigor and Validity**

Attention to rigor is critical with this design. In interpretive description it is important to be explicit with any potential or experienced bias on the research findings. The researcher for this project is a registered nurse who has worked in a variety of health care settings in both rural and urban environments. The researcher has worked in surgical units as well as in the critical care environment, specifically two coronary care units, two step-down cardiac care units, and one intensive care setting. The researcher has also worked as an educator in an academic institution working with undergraduate nurses at all levels of their baccalaureate program. As a registered nurse and educator, I believe that all individuals have the right to free and necessary medical care in a timely manner. I think each individual should work with their healthcare professional team to develop a treatment plan that works best for their own situation. Information should be made available to the person as needed. This information can take a variety of formats such as electronic information found on a website or may be paper based such as on a discharge information sheet or instructional booklet. I believe that learning should start as early as possible in the hospital for the individual to ask questions and seek any additional information as needed. I think that all people are deserving of health resources and should have equal access to these health resources in any setting and in a timely manner as they require this help. Several times, I found myself reflecting on these beliefs, which is reflected in the journals kept to document the process.

Repeated interviewing was conducted to challenge or refine the interpretive description. (Thorne et al., 1997). Health care professionals were presented with information on how the website was used after participation. The caregivers were interviewed following their involvement. Reviewing the use of the site after the caregiver's involvement allowed for

triangulation of data.

Multiple data sources were used to provide triangulation of the use of social networking and to contribute to the trustworthiness of the findings. Data triangulation involved the collection of data from multiple sources in the same study to obtain diverse views of the phenomenon (Burns & Grove, 2009). Focus group sessions were conducted with the health care professionals at the beginning and end of the research project. Interviews were conducted with the caregivers before and after participation on the Living Well with Heart Failure NING site. Caregivers living in urban and rural areas were included to understand if there were any differences. This multiple data source approach provided an opportunity to examine social networking from the perspective of both health care professionals and caregivers at different times and in different settings (Burns & Grove). The findings were also reflected upon in relation to the theory of online social support (LaCoursiere) to provide a level and depth of analysis as well as the current literature.

## **2.8 Scientific Rigor**

Credibility, auditability, and fittingness are three primary standards of rigor common to qualitative studies. Credibility relates to the trustworthiness of the findings. To establish credibility, participants guided the inquiry process (Charmaz, 2005). The interview questions were modified according to the incoming information from the participants, which allowed them to guide the inquiry process. Electronic recordings were transcribed verbatim, and the coding reflected the language used by the participants so that the codes and categories could remain close to the primary data. Memos were kept on insights and ideas generated during data analysis. The electronic recordings, transcripts, field notes, memos, codes and concept maps provided an audit trail of all of the decision the researcher made at every stage of data analysis. The



participants consisted of health care professionals and caregivers providing care to patients with heart failure registered with the HFC between January and August 2015. This research study examined a single center educational and social support website which was nurse moderated and directed to caregivers. Participants were invited to participate if they could read and write using English. Participants were also required to access a computer and be able to follow instructions on how to access a website. This data along with the participant demographic data will potentiate the transferability of research findings.

According to Sandelowski (2007), "Determining adequate sample size in qualitative research is ultimately a matter of judgment and expertise in evaluating the quality of the information collected against the uses to which it will be put, the particular research method and purposeful sampling strategy employed, and the research product intended" (p.183) Others, such as Mason (2010) emphasize the "litmus test" of saturation as the guiding principle to determining sample size. In this exploratory research study, the quality of the information obtained from the person, situation or event is the focus. Data saturation occurs when no new information is gathered. In this case, data saturation occurred in several key areas such as defining heart failure, the signs and symptoms experienced, the suggested provincial focus, and the need for increased participation, with the participant enrolment. The low number of postings posed a challenge for data saturation using the online information (Im & Chee, 2006). More participants using the website would have increased the quality of data. The online forum discussion also posed a challenge. Given the asynchronous nature of an online support group, caregivers may post messages or replies at any time that suits their schedules which means that posting may be spread out over time. In this study, it was hard to achieve saturation online. In order to get saturated information, caregivers were asked a minimum of 10 times and thus to reach saturation on the

website postings, caregivers would have needed to go back on the site and post more frequently.

## **CHAPTER THREE**

### **Results**

The results that follow provide an insight into the use and engagement in a social networking site as a means for caregiver support and information. The section has been organized according to the description of setting in which the research took place followed by the review of the Saskatchewan Heart Failure Network NING site, the use of Living Well with Heart Failure NING site, then exploring how caregivers define heart failure, their situation, and perceptions regarding social support. It also provides information about social networking tools, and under what circumstances caregivers use social networking, and if there are any consequences of using or not using online sources of information and supports from the perspectives of the select health care professionals and caregivers.

#### **3.1 Setting**

The Regina Qu'Appelle Regional Health Authority is the governing body of the Regina Qu'Appelle Health Region (RQHR, 2011). The regional health authority is responsible that all medical programs are delivered and monitored safely on behalf of the residents in the RQHR. The Health Region covers approximately 26 663 square kilometers and provides health care services to many towns, hamlets, rural municipalities and First Nations communities (RQHR). The RQHR is the major referral center for Southern Saskatchewan. Health care services are provided through two tertiary care centers in Regina, a rehabilitation center, primary health care centers, independent physician offices, and many community sites (RQHR).

The HFC was established in March 2008. The clinic is located in one of the tertiary

hospitals in an urban center. The clinic is staffed by five physicians, one nurse, one administrative assistant, three pharmacists, and one dietician. The clinic is open three days a week and schedules office appointments on Tuesdays, Wednesdays, and Thursdays from 1300-1630 hours (B. Hiebert, personal communication, April 22, 2016). On average, the clinic sees eight patients per day. The clinic has admitted over 887 patients to date and has 320 patients actively receiving treatment (B. Hiebert, personal communication, April 22, 2016). Common reasons for admission include a diagnosis of systolic dysfunction, non-ischemic cardiomyopathy, chemo-induced cardiomyopathy, alcohol-induced cardiomyopathy, and right-sided heart failure (B. Hiebert, personal communication, April 22, 2016). The clinic sees on average 100 new patients each year, as many patients continue to receive care from their cardiologist or internal medicine physician. The HFC is housed currently in a medical unit of the hospital. Originally, the HFC was located in the cardiac surveillance unit; however, at the beginning of the research project the cardiac surveillance unit was relocated to the other hospital in Regina, and a medical observation unit was placed in the space.

### **3.2 Demographic Data**

The interviews were conducted with six health care professionals from the RQHR and six caregivers. The health care professionals included four females and two males. All caregivers were female and assisted their father or husband diagnosed with heart failure. All caregivers and family members were involved with the HFC. Three caregivers lived in an urban setting close to the HFC and three caregivers lived in multiple rural settings approximately one hour to four hours away from the HFC. The caregivers' family member was diagnosed with heart failure between one year to 12 years from the time of the first interview, with a mean of 5.08 years, a mode of 4 years and a range of 11 years. The ages of the caregivers ranged from 35 years to 89

years of age. The caregiver and family member were scheduled for follow-up appointments about every four to six months with the HFC. There was no discernible difference between caregivers whether living in rural or urban environment or between those individuals newly diagnosed versus those individuals living with the diagnosis for a longer period of time.

All participating health care professionals specialized in the area of heart failure. All health care participants actively worked with patients diagnosed with heart failure at the time the research was conducted. The health care professionals represented a variety of professionals consisting of registered nurses, pharmacists, and dieticians who specialized in heart failure and were employed at a hospital in the Health Region. The health care professionals reviewed the Saskatchewan Heart Failure NING website and provided feedback about the educational content provided on the site, as well as the readability information and visual appearance. The Saskatchewan Heart Failure Network NING had ten original forum postings by the researcher (Appendix M). Topics included a welcome posting that provided the rules for using the board when communicating online, basic information about the heart with a brief description of systolic and diastolic heart failure with pictures, weight loss, smoking cessation, the RQHR's cardiac rehabilitation program, symptoms of heart failure, a healthy diet low in salt, medications, travelling, and additional information about various treatments and procedures currently available. Information was linked to the Heart and Stroke Foundation website or other educational resources available in a paper copy to patients recently diagnosed with heart failure at the time of writing.

### **3.3 Saskatchewan Heart Failure Network Review**

The healthcare professionals found the Saskatchewan Heart Failure Network NING site user-friendly. The health care professionals were interested in the use of website that helped

people to manage their health. One health care professional commented that "I personally think it would be very useful for the patient population that are able to use the site, for them and their caregivers to get information." Another health care professional agreed and stated, "I'd say the number of patients that come through the clinic where we work is increasing, the number of patients who would use a website is increasing...whether it's that we're getting the next generation of just that even the older generation is on computers more. Either way, I think there's probably more Internet use and less paper use."

The health care professionals liked the ability to post videos on the site and found that the included information focused on the main topics. One health care professional stated, "you have medications, you have the the (sic) teaching of smoking cessation, you have the a great video you know pathology of what's going on so that teaches them." One health care professional liked the multiple ways of the learning that the website provided, such as the use of forum postings, videos, links to websites and sharing experiences with others and stated:

I'm not a patient and I've been fortunate through my life to avoid it most of the time, but I find in these chronic situations, like with heart failure, patients are interested for sure in what's going on but they're mostly interested in what to expect and um so I find the more that we can do that and we try to explain what to expect, but the number of ways that you can show it to somebody or have another patient explain what to expect at what points, that is usually the biggest thing.

The topic around travel became an important area for discussion as one health care professional stated, "a lot of our heart failure patients, they travel a lot. Do you have information, I didn't notice on you know what coverage they have? Because they're always calling me about that. Am I able to travel, I just had changes done two days ago." Given the need for information about travel coverage, the health care professionals felt that the Saskatchewan Heart Failure Network would be more beneficial to those living in Saskatchewan. One health care professional commented, "I think it's more specific for Saskatchewan because there's a lot that isn't covered.

And when they do find out that they're not covered oohhh they're very upset. Like they've paid Group Medical™ or MSI™ for years and then- I think even for heart failure they're not supposed to travel for a year even. They would have no coverage." The health care professional furthered:

And then they've got Great West™ or something like that, like the younger generation have their own group health plan so they can travel. But it's like the older generation that just have MSI™ or Blue Cross™ or whatever, there's definitely stipulations on it. And even like there's the Snow Bird's™ insurance that's out there as well that they can get out of Winnipeg or Edmonton or Calgary I do believe, and sometimes they can't even find what to do call someone to cover the. And they'll often say they have to be stable for a year before they travel. So that's something that is huge. And yet I try to answer those questions which is very hard to answer and if they had a site to go that they can go to pertain to that.

Exercise was another point of discussion with the health care professionals. Health care professionals wanted the focus to be on exercise. One health care professional stated, "if they see that here they'll go oh she's seen it there and there." Another health care professional stated, "that's just it, so many of them don't realize that they just do the same thing every day and trying to increase on that is huge for them and it's so helpful."

Health care professionals liked the links to treatments and procedures and found that information to be useful. Many health care professionals found patients using the Internet to look up new treatments and procedures. One healthcare professional commented "do you have a spot with research too, new stuff that's out there but not available? Do you know what I'm saying? Because they always come with this stem cell thing or something and I'm like oh my God we don't do that....yes they Googled it." Another health care professional agreed:

yeah there's probably a bit of myth busting that should occur, and I think could include stuff about new drugs, new therapies, stem cell therapies, and even why it is called heart failure. Things like that I think sometimes frightens patients. So there's some myth busting and there's also some horizon scanning that they're interested in so that they can get an idea of how forward these types of things are. Just because a new drug has been shown in one study to have benefit, it doesn't mean it's even going to come to market. It could take years and decades.

Health care professional stated that patients were not always getting medical information from reliable resources. One health care professional said that the patients search for medical information from sources such as "Googling or TV, they just watched it on TV and some channel it's not available here, probably in South Africa or South America or somewhere something. And the newspapers. Like that guy actually found it in a newspaper, so they're looking everywhere." Other health care professionals felt that the most common website used by patients and caregivers were the ones that appeared first on their search engine. One health care professional stated "it's the lower threshold stuff. It gets delivered to their house, it's being able to Google it and whatever comes up first." Another health care professional furthered the statement with "if it comes up there it has got to be good."

When asked about encouraging patients and caregivers to use social networking sites, the health care professionals responded that they would help their patients and caregivers to use such sites. One health care professional stated "especially if as an organization we have input into what's on it. So we are aware of it and we know that the information there is good... we've give them a little card and tell them to visit that." However, the health care professionals also identified risks when using such sites and liked that the website would be moderated. One health care professional stated, "and this is probably being too paternalistic, there could be the occasional patient who you don't necessarily want participating in unmoderated types of discussion where they could take an inch for a mile kind of thing. And I think some patients could get scared off or fear monger or whatever it happens to be."

Another issue that arose was the title of the networking site, Saskatchewan Heart Failure Network. One health care professional did not like the use of network as it did not clearly identify who belonged to the network such as if it included all health care professionals or all



patients and caregivers. Another discussion arose around the use of the words *heart failure*. One health care professional commented:

occasionally patients have never heard that they have heart failure. And I think more and more people are getting use to using the term heart function issue or heart function disorder or something like that. So I don't know what the solution is but just making a point of it that if we as a health care community keep calling it a heart function disorder or something along these lines and then all of a sudden we send them to this website called the Heart Failure Network it could be shocking.

Another health care professional furthered the discussion by saying that many of the patients do know the term heart failure as it comes from the Canadian and American Heart and Stroke Foundations. She stated:

I know in our care plans we used to always put cardiomyopathies as their diagnosis. So at the same time I don't think they recognize either I'm sure if I handed someone a cardiomyopathy handout now. And a lot of people don't like the negative term of "failure."

One health care professional offered an example about the negative connotation of the use of heart failure in her experience:

one guy said to me that he didn't like heart failure clinic because he tells his buddy 'oh I'm going to the heart failure clinic and the guy is like are you dead? Are you not doing good? He says no I'm fine.' And that's when he said to me could this not be named something better?

The health care professionals chose to change the name from the Saskatchewan Heart Failure Network to Living Well with Heart Failure as it "sounds positive."

### **3.4 Living Well with Heart Failure NING website**

The Living Well with Heart Failure NING site was developed incorporating paper copies of patient information booklets available to patients at the time of writing and through discussion with the health care professionals during the focus group session. The Living Well with Heart Failure NING website was developed using NING 3.0 interface, which was the current version

of NING at the time of development. The security features used were the same as found in the Saskatchewan Heart Failure Network. The second website was developed so that caregivers would have their space so they could co-create by responding to discussions, adding forum questions, or other content such as videos or website links. A section of the site allowed caregivers to join individual groups to discuss any topics of their choice. All forum posts were previously approved by the health care professionals and then pasted and copied onto the new website. The new site provided more designs with an easier layout for the caregivers to follow discussions. Caregivers started joining the site in July 2015 and continued to access the Internet site until October 2015. In total, four caregivers actively posted on the site. Of the two remaining caregivers, one caregiver read the posts on the site but did not post and the second caregiver was hesitant to use the Internet site as she did not routinely use a computer. There were 15 postings by the four members, the number of postings varied by participant. For example, one participant posted twice and another participant posted seven times. Topics of interest for the caregivers primarily related to medications, traveling, healthy diet, and symptoms of heart failure.

Caregivers shared their personal experiences on the website with the other caregivers. Many chose to exchange information about their individual story of living with heart failure. For some caregivers that meant the situation leading to diagnosis such as the information shared by Jessica:

Just a little back story. My husband was diagnosed with heart failure last summer after passing out at work. He is 39 years old and "was" in good physical shape. After a month in hospital we were permitted to go home after he received an ICD [implantable cardiac defibrillator] implant. His condition unfortunately has not improved as hoped and we are currently waiting for him to be added to the transplant list.

Green also shared how her partner was diagnosed with heart failure:

I don't know where to start; my partner first had heart surgery in August of 2008. HE (sic) had 8 bypasses and a pig valve replacement. It did not go well it was a long surgery. He ended up in the hospital in intensive care for 15 days before he came too. They kept

him in the hospital for 5 weeks. After he came home he went into heart failure twice. After he was able to get onto the cardiac servalance(sic) unit at the [name] hospital and was monitored every 4-5 months things started to improve.

Others chose to post about situations that arose in their day-to-day lives around medication, travel, and diet. For example, Green shared that her husband never misses his pills in part to using medication blister packs as she stated, "my husband is on a lot of medication, he never misses his meds. The fact that we have a new bubble every time he gets refills helps a whole lot." Sandra agreed, "The bubble paks (sic) are wonderful. My husband loves these paks(sic) as they are easy to use and easy to trac (sic) Best thing that happened to his meds."

Traveling was another important area of discussion for the all four caregivers. Sandra shared her concern around traveling with equipment and stated, "We went on a holiday, and we did ok I wasn;t (sic) sure about taking the defibralltor (sic) monitor but it was easy to deal with. We only had to plug it in and that is all we had to do. The most bulky item was carting the scales around but that really wasn't a big issue (sic)." Susan then asked how Sandra managed eating out or if they ate primarily home cooked meals. While Green responded by sharing that she and her husband no longer travel, "We have given up travelling. My husband is 80 years is partially blind is diabetic and heart problems. The last time we travelled was 8 years ago and find we are happier and more comfortable at home. I guess it goes with being brave and where you feel at ease and comfortable." Sandra supported Green's statement in her reply, "I can certainly understand that. We are still in our 60s but would not travel outside Canada. My husband likes to go to Vancouver Island for part of the winter because it is green & he can get out & about easier without the cold, snow & ice. It is just a long drive getting there." Eating out while traveling became another area of discussion as Jessica stated:

Sodium when travelling is a major road block for us as well! Packing snacks is a great idea and we always try to hit up a supermarket in our destination city to have fresh fruit and veggies and whatnot to keep in the fridge in the hotel. If we do have to eat a meal or two out we always spend some research time on menus and nutrition guides and take it from there!

Sandra agreed with Jessica's comment and shared:

Travelling is an issue for us mainly because of the eating out where we have no control of the sodium/salt used. We never eat in fast food outlets any more. I pack snack food for us such as unsalted nuts, raw vegetables (sic) & fruit but still need to have meals. Any one (sic) have some tips or ideas?

The discussion around diet focused around decreasing salt intake. Jessica posted the following comment under health eating:

One of the hugest eye openers in this entire heart failure learning process was definitely (sic) how much sodium is in everyday foods that we always ate and never gave it a second thought! Cooking from scratch has become a huge thing in our household but I do find it a challenge for quick meals during the week. We've tried the MS. Dash spice blends that are sodium free and I like them as an addition to slow cooker meals! Anyone else have any quick meal tips?

Susan responded with another way to decrease salt and to improve flavor through the use of seasonings:

Epicure has a variety of herb spice blends without salt. They are quick to use for seasoning almost anything. As you say cooking from scratch is big in our house as well using a lot of No Salt added ingredients such as No Salt can tomatoes, broths, salmon etc. It is amazing what you can find in the stores. I make all our soups in big batches and freeze in meal size portions so that is always a quick lunch. I like to have a variety in the freezer. Also very simple meals like BBQing meat with no salt seasoning with vegetables (sic) and fruit is quick.

### **3.5 Life as a Caregiver**

#### **3.5.1 Defining heart failure.**

For the caregivers, heart failure had varying but similar definitions. One caregiver described it as "death" or a "dead heart" while five others defined it as an injury to the heart such as from a cerebral vascular accident or myocardial infarction. One caregiver stated, "I would

probably define it as just inability for your heart to keep up with your body. Your heart's just not working; it's broken. It's just not working right, and it affects every other part of your body."

Another caregiver stated that she did not understand the meaning of heart failure until she experienced it for herself as she stated "to me I would say like I've learned because he's got congestive heart failure that he has heart failure. But before I knew what I know about him now and how he lives with it, I would have said heart failure was somebody that's had a heart attack." For many of the participants, heart failure was more a description of what their loved ones could no longer do as the disease process has "slowed" them down. One caregiver commented that "he's not as mobile now as he was. His mobility has slowed considerably in the last year. He has a scooter, so he uses that more than ever now." Another caregiver described heart failure as "not [being] able to do what he used to be able to do. He gets out of breath when he walks; he cannot walk very far." While another caregiver further described other physical effects of heart failure and stated that "he has no appetite, do you mean something like that? He has very little appetite and he has lost 40-50 pounds, and he's lost short-term memory." The physical impact of heart failure was discussed by all participants and influenced their day-to-day life as one caregiver acknowledged that the heart is "not letting him do the things that he used to be able to do full bore, and we just cope with it."

### **3.6 Living with Heart Failure**

#### **3.6.1 Knowledge deficit: Understanding signs and symptoms.**

Caregivers described many changes to their life situations based upon the diagnosis of heart failure. For a few caregivers, understanding how to learn to live with the disease process and knowing the signs and symptoms of the disease process were important. Common symptoms reported included shortness of breath and walking slower. As stated by one caregiver:

A lot of his was, and still is, shortness of breath, coughing, especially laying down, so he has to prop himself up. Just weakness in general, tired. He has an ICD so that helps if he has an uncontrolled arrhythmia, he just had one shock in the last year, so that was interesting. And a lot of it I think the biggest thing for him is he retains so much fluid so he's on fluid restrictions and on everything else. But the Lasix doesn't cut it all the time and then he gets a big belly and all that good stuff that goes along with it, and the IV Lasix and all that good stuff. But I think most of it is general weakness and a little bit of psychological things that come along with it. Like you can't do a quarter of the things that you used to be able to do so that's a big part of learning to live with it, and learning to not freak out over every little thing I guess like we used to. At first, I was like why are you coughing. We should probably call. And you learn slowly that these things are just part of having the condition, and you have good days, and you have bad days. And that's a lot of what we deal with on a daily basis.

The caregiver also wanted to know about the end of life symptoms and other symptoms that required immediate attention as she called herself a "planner." She stated:

Like I would really like to know that. I know maybe that doesn't sound right but I would like to know that. You can't prepare, anything can happen, but I do know that – we went to the pacemaker clinic and they said if the defibrillator goes off it should be okay but if it goes off twice in a row get to the hospital ASAP. So hopefully that would be in Regina because they don't have anybody in Moose Jaw. Well, they've got two internists but I don't know if they could cope. I would feel better in Regina.

Another caregiver wanted additional knowledge on day-to-day needs related to specific treatment options as expressed by this caregiver "like we didn't know fully I guess what the transplant process was going to entail and that we would have to live in Edmonton for 3 months. Well how do you live there and maintain your job and pay for it."

### **3.6.2 Changes to activity: Activity intolerance.**

For all caregivers changes to mobility impacted their lifestyle with activities such as employment, travel, and other recreational activities. Many caregivers commented on a slower walking pace or on how easily their loved one tires and takes rest periods. Other changes related to lifestyle such as previously traveling. Some of the caregivers traveled out of the country for the winter; however, following the diagnosis many stayed at home or in Canada due to a variety

of issues such as medical coverage, fatigue, and change in activity. One caregiver stated that they are unable to leave as "he can't leave Canada because of insurance, insurance purposes. We went to the States for 21 years." One caregiver commented:

he basically stopped farming; I mean doing very little on the farm. So that reduced my involvement as well. And then also he was an outfitter and a trapper, and we used to spend a lot of time in the bush you know on ATV's and snowmobiles, and he couldn't handle that anymore. He couldn't handle an ATV or a snowmobile, and he ended up having to sell his business. And I was involved with him in that too. And then the other thing, I was working, and I continued to work, but I was away from home like I worked away like I'd be gone for two weeks at a time and then sometimes I was working closer to home but still out of town all day. And I continued to do that for quite a while and then it just sort of got to a point where it just wasn't good for me to be away because if he got sick and I wasn't here, or the fact that when I was away he was always eating out and that was not a good thing. So then I just thought I would retire and then I then be at home.

Although one caregiver stated that there was not much change to their lifestyle she did comment that:

It hasn't changed that much. We still do the same things. We're not partiers or anything; we like staying home, always have. And when we're out I do know that we can't walk faster, I have to walk at his pace. You always have to keep him up front so that he doesn't feel like he's I guess an invalid. So I try very hard not to let him feel like that. And it's working, he's good. And if I say something I don't say you, I always say we. It's always we it's not you or I, it's we, and I think that helps.

### **3.6.3 Changes to routine: Impaired walking.**

Several caregivers commented on how the diagnosis changed the way they performed their exercises. The form of exercise changed. One caregiver said that "he tries to walk 5 minutes on the treadmill, but I think it tires him, so he doesn't bother with that anymore. He just ah he walks around the yard, and that's okay. But I see more and more of him sitting more frequently, and he sleeps a lot." Another issue related to safety considerations following diagnosis. Previously the family member may have walked around in an outdoor area, and now they required walking in a monitored facility to ensure safety in case of a medical emergency. One

caregiver commented on little ways their activity changed:

They said while you're just getting back to trying to have more normalcy, don't walk alone at night down a back alley, that kind of stuff, that you think would be common sense but if those are things that you've always done you would think nothing of getting up at 5:00 in the morning and going for a walk if you always had done it right so. But that's probably not the safest time to do it. Or just have someone with you and all that kind of good stuff.

#### **3.6.4 Travel.**

Many caregivers shared that traveling outside of Canada stopped. One caregiver stated:

We don't travel. He doesn't, we just don't. He just likes to be home as much as possible. We go out a couple of times a day, or we do our shopping, and we have coffee at the mall with our friends and that's our social life.

Another caregiver continues to travel only within Canada due to restrictions related to the disease process and need to have travel insurance. She stated:

This past winter when we were in BC he was very sick, and his heart failure was really bad and he had rapid atrial fib and all of that. And the doctor had suggested there that we should not be traveling, that we should really think about whether we should be traveling or not, which was kind of a downer. But then we got back here and saw [cardiologist], and things are really good, much better, and so I don't think [cardiologist] would advise us that way, and our family doctor too said if I was you I would travel, but in Canada only, because we're limited. Like we wouldn't be able to get insurance to go outside of Canada.

### **3.7 Sources of Support**

#### **3.7.1 Heart function clinic.**

##### ***3.7.1.1 Source of medical information.***

The HFC provided a source of medical information and social support. Caregivers commented that they received medical information on topics such as diet, exercise, medications, and monitoring weight. For one caregiver, the HFC served as her first source of medical information support if any questions or concerns arose following discharge from the hospital. One caregiver stated, "at first we were contacting her [the registered nurse] more often, but now it's just when



we go in and have our appointments that we talk to her." Caregivers also contacted the HFC when their loved one was readmitted to hospital as one caregiver stated "if something came up that he was taken into hospital I'd probably phone and let her know or something. I've done that." Another caregiver commented that the health care professionals are her primary source of information, "I shoot her an email, and she checks with the cardiologist. We pretty much use the HFC as our go-to now for everything." The HFC also provided a sense of security as noted by this caregiver: Because of the clinic, you're so well monitored you know that it takes a lot of stress, or

you know worry that I know that he is being monitored. It's not like I have to make a doctor's appointment when he's not feeling well. I know that we're going every four to six months so to me that's a huge help. Because I know if he's not feeling well, well you know we've got an appointment in a month. So I just pay attention to how he's feeling and just let them know every time we go there.

The HFC was considered trustworthy not only for information but with medical care. Several caregivers commented that they trusted the medical advice of the HFC over that of another general practitioner. One caregiver stated:

in the last three years we have not gone to the regular doctor a whole lot. Certainly for anything heart related I would call the clinic before I would call the general practitioner. I have complete trust and faith in what they're going to tell me. Like you know I think they know more about my dad than the GP does, especially because we have a new one because they all moved.

Another caregiver shared her frustration on receiving differing medical advice from their general practitioner. She stated:

Oh, we've had such good – the experience with that by going to that clinic. And they've gone through our medication if we're concerned about something. Like he was experiencing a lot of diarrhea, and stuff and he went through over and over his medication and changed stuff. But I think doctor ... our heart doctor... what's his name, [name provided] he's changed medications, and then we go to our family doctor, he'd change it back, and they'd play tag you know with this? Because our family doctor thinks his blood pressure should be up higher and [cardiologist] says no it should be kept low, so and he was trying to get him to the top of this pill to give him a better quality of life.

So anything that was frustrating and he's written two letters to our family doctor about it and he just can't figure that out. And he'll look at his medication, and he'll say no I don't agree with that. And I'll say well the heart doctor – so it's kind of like they play tag with each other sometimes on this medication bit, and I don't know. Like I think if it's for your heart it should be your heart doctor that gives you the medication, and you should be in charge for your heart. And he's in charge of his medication for his insulin and his diabetes. Anyway you know anyway that's been frustrating.

Caregivers also viewed the care received in their provincial HFC to be more trustworthy than other provincial clinics due to the relationship built over time and several appointments.

One caregiver shared her experience of going to another province and stated:

Sometimes I find that there's not really a breakdown, but you'll have different doctors that have different opinions and then you're like okay, so who's right? We still go through a little bit of that sometimes. You're always going to have different doctors that have different opinions and that's fine, but sometimes you feel a little like I don't know lost because you just don't know – is Edmonton right or is our guys right? Like you know...

One caregiver's only source of social support came from the HFC as her husband did not want to notify family and friends of his diagnosis. She stated:

it wasn't until April of 2015 that he actually allowed me to tell the family. He didn't want anybody to know so it was a whole year of not telling. They knew we were going to the heart clinic, they never once said what for? We just said to go see [NAME DELETED FOR CONFIDENTIALITY]. And finally when he was going to have to have the defibrillator I said now maybe it's time to let the family know, and I did and um. Our two daughters phoned because I texted everybody so they'd get it all at the same time and yeah, the two girls phoned, and they were a little upset, and I said just a minute here's your dad, so he dealt with it.

### **3.8 Sources of Information**

Caregivers used a variety of informational resources to learn everything that they could about heart failure such as paper-based information tools and the world-wide web.

#### **3.8.1 Paper-based information.**

For the majority of the caregivers, much of the information learned to date about heart failure was provided in print. One caregiver commented that "I read anything I find. If I find

something in a paper or in a magazine I usually read up on it." Others rely on the information presented to them while in the hospital or from the HFC. One caregiver stated, "usually I review the information that we have. I go back, and I read it or try to go on to the Internet, and I'm not very good at that." While another caregiver trusted information received from the HFC health care professionals and commented:

Me personally being my age I guess or old school, I would sooner put a lot more stock in talking to a doctor or other people rather than just online, like the Google thing. I don't like to Google a whole lot because you can find whatever answer you want kind of thing. You know in this instance I know a particular site that's different, but that as opposed to just Googling something, I don't like to Google. But if the heart clinic told me to go to this site then I would totally trust that and use that. But I'm not a big fan of Google.

Several caregivers showed their teaching handouts to the researcher. These teaching handouts were provided by the HFC stored and stored in the kitchen or the living room for quick reference.

### **3.8.2 Just Google it.**

Caregivers used the Internet for a variety of purposes as indicated earlier. Several caregivers used it to look up medical words and other medical conditions such as Crohn's or paronychia. One caregiver stated her search for information on the Internet increased after her husband's medical diagnosis of heart failure. She stated:

I would say when this first happened I would spend at least five-six hours a day, constantly. Anytime I was on my phone that's what I was doing, was reading this or that. Now maybe once or twice a week I'll look up something right. So I think that's always – when something initially first happens it's always overboard research mode.

Typical websites used by the caregivers included the Mayo Clinic and the Heart and Stroke websites. The amount of time currently spent on the Internet varied from daily to monthly. The majority of the caregivers rated the credibility of information available on the Internet quite high at a four or five on a scale of 1-5. One caregiver who rated the credibility of online information

at a four commented that "I think it's all credible in its own way, I just think that the average person doesn't understand it [the information] as it's meant to be understood." She explained her reasoning as follows:

Kind of like going back to if you have someone who did a study on a certain drug and how it affects people with heart failure. Well, they're looking at you know they have 1,000 people, so out of these 1,000 people this drug caused X chromosome to do something crazy in here. I don't understand any of that. So really its useless information to me right. But to someone who does understand it maybe it's got some validity behind it. So I guess it's hard to say whether it's credible or not because I don't understand it, to begin with right. So I think once you start reading things like that you start picking out words that you know – like mortality rates, and you know like so you're looking to understand what they're talking about, but you're picking out the worst of the worst right. So again your take away might be a little skewed, the information might be right, but you just don't understand it.

Two other caregivers rated the credibility of information on the Internet at a three based on the site and the ability to find an answer to their query. One caregiver stated that she did not trust websites that offered to have a medical professional speak personally to you with use of a chat feature. She stated:

Mainly I go onto the what's that one Mako? Mayo Clinic, usually that's what I hit. But then you get somebody that wants a doctor to talk to you or something, and I just get off of that, I just don't bother with that nonsense, because I don't know who they are or whatever.

Caregivers used the Internet to search out health information, but then seek the advice of a medical professional as in this situation:

It's not that I would do exactly what it says. I would consult with my doctor. I wouldn't just go you know in there and get pills and order them, like where you can from the States and stuff. I wouldn't think of doing stuff like that. That would be a risk.

Over time, their self-reported Internet usage decreased due to learning to live with heart failure and taking it "day by day" or as a result of concerns around the quality of information as noted by one caregiver:

Looking for health information is tedious. I try to stay away from it now. At first, it was I

was on Google you know 16 hours a day. Everything you find is, I'm a big statistics person and I like statistics but what you start to realize when you're reading all these things is that their statistics based on a study with a particular group of people with a particular group of symptoms, and they're not very generalized. Then you start looking at things like mortality rates and well if you're admitted to the hospital X number of times since your discharge your mortality rate goes up to this. And I think it's just for the average person, myself included it's just you don't know enough to take that information and be able to be like well that completely applies to us. People who make these studies, the studies are made for a reason, and they're not meant for every like layman to read. They're very technical as studies should be.

### **3.9 Living Well with Heart Failure NING site**

#### **3.9.1 Interest in the use of social networking.**

Before using the Living Well with Heart Failure NING website, several caregivers stated that they were not interested in using social networking for social support or health information. One caregiver felt that she was receiving all necessary support and health information from the HFC. When asked if she was interested in a website that helps people manage their health, she responded with, "no really, no. I think I'm getting enough right now anyway. Maybe at one time I would have in the earlier part." Some caregivers chose to participate to help people newly diagnosed with heart failure and caregivers. One caregiver stated she chose to participate because:

If it's anything like the clinic, I think it could be very helpful. Like yeah. It's hard for me to say because I've just gotten into this in the last, become the caregiver for the last five years. But I could see you know where if this was 20 years ago, if my mom was still looking after him, I could see her making use of it or learning from it, hence why I would agree to participate in this. Because if it is something that could help people, anything like the clinic, then I think it's great.

A second caregiver agreed that the Living Well with Heart Failure NING website would be useful "for those people who are newly diagnosed." She stated that "it would be nice to have a central location where you don't have to hit 18 links in 18 different websites, and then all of a sudden you're in some hospital in Pennsylvania's website. So it would be nice to have something

that's relatable to living here." Another caregiver chose to participate based on potential learning from other caregivers and stated, "I think what you're doing with having the caregiver website, I think that would be very good because you're able to share with other people who are experiencing the same thing. So I think that would be really good." Others were interested in learning from other caregivers and "maybe getting ideas from other people and how to umm manage you know different situations."

### **3.9.2 Suggested audience.**

Following participation on the Living Well with Heart Failure NING website, all caregivers found the site useful for those dealing with cardiac problems. The majority of the participants found it helpful for both newly diagnosed patients and caregivers, but stressed that the site would be used differently depending upon the needs of the individuals using the forum. One caregiver stated that "I think everything that's on there could be useful to various people depending on what they're dealing with or what their interest is at that time you know." Another caregiver stated that "I think everything was useful to someone right, even if I didn't find it particularly useful to my situation I can see how it would be useful to a brand new person with heart failure. So I think everything had its place."

One caregiver stated that information about the Living Well with Heart Failure NING site should be provided at Orientation to the HFC. She stated, "like you know when people start going to the HFC like this could be something that's in your orientation. Like here's a website, check it out, it's going to give you so much more information. And sometimes health professionals don't have all the time in the world to answer every question you have, or like us we forget the questions we were going to ask." Another caregiver commented that the site would be valuable to those only seen by their family physician:

I think people that are maybe newer to congestive heart failure or maybe don't have, like I mean we have such good access through the Heart Failure Clinic in Regina, but I mean not everybody gets to go there, and I don't know if they have anything like that in other centers, like Saskatoon and Prince Albert or Yorkton, like whether they have. And if they're mainly just dealing with their family doctor I think that it would be a good resource for people.

### **3.9.3 Ease of use.**

All caregivers commented on the ease of use of the website, indicating it was easy to navigate and to monitor recent activity as commented on by one caregiver:

I liked how you could see what the latest posts were. So I mean you could look at things like this has been posted since I was last on so I think that was good, that you know they were in order. So the most recent ones at the top so you could immediately see what was new since I'd last been on.

Another caregiver found the information presented in a welcoming manner which she felt would encourage people to come and use the website as "it is a good source, and it's not overwhelming, it's not like there's too much. And it's easy to access it's not difficult that way. So it would keep you going back because it's not hard to use I think." Health care professionals felt that the website allowed for reinforcement of prior teaching given the information was easily accessible and that participants could learn from each other. As stated by one health care professional:

Everything I looked at because you need to know what symptoms you need to be looking out for and even though they may know, but sometimes – like I work on MSU, and it was CSU and people know all this stuff, but they still don't lose the weight, they don't exercise and whatever so you really do need a lot of reinforcement. So getting all the information repeatedly isn't a bad thing and just things you need to look out for, medications is a huge thing, and side effects. I liked how they were all broken down into the different groups of drugs and what you need to look for.

### **3.9.4 Sharing experiences- Functional support.**

Several caregivers commented that accessing the Living Well with Heart Failure NING site was valuable in connecting with others who had similar experiences. One caregiver said that she checked the site "just to see if other people are having, what issues were coming up with

them and you know if they were having any problems if I might have been having the same problems." Another caregiver used the site to share her experiences as a caregiver:

I always went into the caregivers, it was really good for me to go on there and say hey this is what's happened with John, well said. Yeah, that really helped me, it just kind of took the weight off my shoulders, just to share. I thought maybe somebody else is having similar problems or whatever, yeah.

Another caregiver felt that even though she knew the information, she still wanted the perspective of another caregiver:

This sounds silly but I liked the, I can't remember what the category is now but the nutrition and the salt intake and the this and the that. Even though you know it like the back of your hand, sometimes it's nice to get different opinions about what do you guys do when you travel? Or in this situation how do you make sure that your significant other is eating properly your...while it's Christmas? That would be a good thing coming up, or Thanksgiving meals or this and that. Those are kind of everyday things that you can put into application right away, which is kind of interesting

Health care professionals felt that sharing experiences would lead to improved self-care behaviors. As one health care professional stated:

I never think you can have too much information when you're dealing with the condition. Especially other people's experiences always tweak things, oh I could be doing this better. And I think you get more insight too about heart and stroke other feedback from other people dealing with the same thing. Because it's not just someone saying do this do that.

Another health care professional thought that it would decrease feelings of isolation:

Just a community not feeling alone I would think you know, that you have people to go to if you're dealing with something specific and knowing you have that place to go to. For me it would give me comfort if I had heart failure. And to me, all of that information, like you can never know enough about hidden sodium and different things like that that might push you over the edge into another readmission. And the traveling thing would be a huge help, just things you need to be aware of and avoid that you might not even realize, even though you think you're making the right choice.

Another health care professional agreed with the importance of social support stating,

and just to share because I think sometimes they feel like they're going through life on their own in this type of condition. They do share in the waiting room but then they go home and they forget that we're all riding this same condition and involved in it. So to



have someone to talk to them is really good.

### **3.9.5 More of a lurker.**

The majority of the caregivers described that they enjoyed reading what others have shared about their personal experiences rather than adding to the topics on the site. All caregivers stated that they actively followed discussions rather than posting themselves as they felt that they did not have anything to add to the discussion. One caregiver said, "Yeah, or even if you didn't say chime in and talk, um if you're reading what other people were writing, it definitely you can be like oh yeah I felt like that or I thought that. " Another caregiver agreed and stated, "yeah I quite often look just to see what was going on and if I didn't have anything to contribute then like I didn't post." Another caregiver felt that they did not post because information was already well known as she stated, "I think I was mostly interested in what other people were saying. I didn't go specifically to find some information very much because like I said we've had a lot of this already. You know." While another caregiver compared participation to her regular social involvement and stated, "I'm not a huge poster, just in life, I'm more of a lurker." One participant said that she did not need the support or information on the site during the time of the research study. She stated, "I didn't go on too many other parts or sites or other people talking because I wasn't needing anything of that." She furthered her comment by stating, "I haven't had any problems, things have stayed pretty steady, so I haven't had any real problems. If I had more.. some problems then I would ask for help on the website." The group forum was one feature not used on the site. This feature provided a means for caregivers to come together to ask questions or share advice. Caregivers could see a need for the tool but did not feel that it was applied to their situation. One caregiver stated:

I think if, again this is just because it's me, I'm not I don't know if I particularly would do that but I could see other people doing it. People have a need to congregate together, so

you can see people I don't know— if you're 60 years old with heart failure, or 70 years old your situation is a little different than someone whose 30 or 40 years old. Not even medically but just in general right. So I think that people will tend to gravitate towards people like that. It's hard to say because you don't want to segregate people too much, but yet there are blatant differences. Even in medications and things. Like sometimes a person who is 70 is not going to be put on the same medication as someone who is 35 right. Just because that's how your body is at 70. That's interesting. I think that I don't know I don't know how you would break it into like that, without alienating somebody along the way. But hey it's the Internet, that's what it's for.

### **3.9.6 Face to Face meeting.**

Caregivers enjoyed having access to other caregivers as one caregiver stated:

I think it's very important because you know what you may be going through something that you don't think anybody else is going through and then you can oh yeah I've gone through that or I'm going through that or Yeah I think it's great. You might not have specifically going through exactly what they're going through but you might have similar, and then you can relate.

Some of the caregivers still wanted to meet face to face with other caregivers as stated by one caregiver,

well the website is great because you can go on it all the time, but I think sometimes it's just nice to meet somebody, talk face to face just for a coffee. Yeah. Maybe not. I wouldn't want to go to a meeting every month. I mean you can go on the website and that's great but sometimes that personal thing helps.

One caregiver felt that it was important for caregivers to have their support groups, separate from their loved ones. She stated "we can always give the heart patient somewhere else to go [chuckle] or just have a meeting for them in a different room. I don't think they should come because with my husband it wouldn't work." She further indicated that he would not participate in a group setting as he is not a "socialite" and prefers to read about the disease process and "not dwell on it."

### **3.9.7 Increasing awareness.**

Caregivers and health professionals felt that more awareness of the Living Well with Heart Failure NING website was needed. Some caregivers felt that increasing awareness through

paper advertising, such as in a local newspaper, in a pamphlet or a card that could be handed out on discharge was required. As stated by one participant,

I think pamphlets are good. Like pamphlets. Even like um hmm when people Google heart failure, maybe you know how do you get your site to the top, do you know what I mean? Because if I'm looking at something I'm always looking at the first thing that comes up right. I've noticed if I'm looking for something, like Googling Costco, Regina's Costco store comes up first right, and hopefully, that would come up first as well if someone just Googled heart failure. Do you know what I am saying? because we always go to that first site, at least I do.

At the beginning of the research project, many caregivers and health care professionals agreed that the intended audience were those caregivers living in Saskatchewan due to factors such as limited access to the HFC and geographic location. One health care professional stated that she felt it needed to stay provincial:

Because I think, there's a huge need for it. Like there's um even Northern Saskatchewan where they're a little bit isolated. They're not as isolated as they used to be, but they have a distance to travel and even if they come to Saskatoon or Regina because we do have some people from PA and Smeaton and places like that that come to the Heart Function Clinic, and if they were able to access it you know that would be good for them, because that's a huge distance to be feeling like you're out of touch with everything, and I think that would make them feel more in touch with the whole group.

One caregiver agreed and stated,

I think it's just nice to have something that's – I don't want to say your own – but that's geared toward what people are going through in this province. That's not to say that people from other countries wouldn't benefit from reading it, but it's nice to have that information that is local.

Following participation on the website, participants felt that the site should have a national focus to generate more discussion. With a national focus the caregivers could learn about various treatments available elsewhere in Canada as stated, "It could help stimulate discussion, like why does your doctor do that or why are they doing that there, why aren't they doing that here. Get them to ask questions on here." One health care professional felt that the local information might get lost but did not overlook the potential of a regional focus for the website. The health care

professional stated,

To get that critical mass but still keep it feeling somewhat close to home I would do regions, like you said maybe Prairies as a region. I mean if there had been enough people in Saskatchewan or within just even Regina then the smaller more local it is the better. But obviously if you found that you might have saturated the amount of people that would use it here ...

One caregiver agreed with a regional focus and stated:

I think definitely it could be international because it's information that's health information that doesn't change no matter where you are. But maybe it would be nice to have a sub-section of, I don't know, if you live in Alberta, if you live in BC if you live in Saskatchewan or whatever. And there could even be assistance links, like things like support groups or things like that that are in your district if you will.

To publicize the existence of the site, many participants felt it was important to have information available on the wards and in doctor's offices. Others suggested advertising it in papers distributed in smaller communities so that people with cardiac conditions could still participate and learn even if not diagnosed with heart failure. One caregiver stated,

It's hard; it seems word of mouth seems to be the best way to get things out. Sometimes columns in a local newspaper. We have a book that that comes out once a month; it's called [name of paper]. It's a newsletter that comes out every month. I don't know if other towns have that or not. Different people write different articles. I think this is the one that's got the Alzheimer's. Everybody reads it in our small community.

### **3.9.8 Need for a moderator.**

Caregivers and health care professionals agreed that a moderator is required on these types of websites to ensure that information posted is accurate and that the online learning environment remains safe. One caregiver stated, "kind of need someone to monitor, because who's out there to check. What you've said is good stuff but what if someone is saying that is not appropriate for heart failure." Another caregiver felt that it was not only important to monitor activity on the site but to be available for online medical help. She stated:

I don't want to say it would be good to have someone policing the site but in a small way, right. Like maybe if someone, I don't know what the word is, say if someone is posting

something in a certain category that should be in another category or you know that this person means something different, but where they're posting it. Maybe to shuffle things around move things to the appropriate part. But I don't know if it's necessary to have someone there 100% of the time but you know sometimes websites will be like live help from.... That might be beneficial for people who have specific medical kind of questions even.

Many caregivers commented on how having additional health care professionals to moderate the website would be beneficial and add more information. As one caregiver stated:

It would almost be neat if you could rotate, like a special guest. From this time to this time on this day we're going to have a pharmacist and you can log in and ask your questions and they'll answer them. Or a doctor or a social worker. That would be kind of neat to have different perspectives from different healthcare professionals.

Others thought a nursing presence was sufficient given nursing training. As commented by one caregiver,

I think like even a pharmacist or dietician, but uh I think as long as you've got a nurse, the dietician, and a pharmacist, but just as a backup type of thing. Not that you...because most of the stuff you know already that would be helpful.

Another caregiver wanted additional health care professionals to join the discussion. She stated, "maybe social services because somebody may need help finding a place or what benefits are out there for help out there financially or whatever for people." Other suggested health care professionals included a dietician, exercise physiologist, and social worker to help deal with the associated costs of living with a chronic disease. As stated by one caregiver, she wanted more information on "how do I pay for these medications, or how do I travel for different tests, or different doctor's appointments."

### **3.9.9 More participation.**

All participants commented on the need for greater participation among members. One caregiver said, "I think it's nice to hear what others are saying, and I think that's a good part. I kind of thought maybe too bad there wasn't more discussion, it seemed really hard to get any

discussion going." Others wanted the site opened to create a larger pool of participants as she stated, "Unless there was more people, like if there was more people who had access maybe you could get more going. Because there was I don't know how many – there wasn't very many was there. No. Maybe that would get more going if there was more people going on and having access to it." To increase participation, one health care professional recommended providing user feedback as heard in the following comment:

are you doing patient feedback or people that participated, like what's it called when you have a little testimonial of just hearing someone else's point of view or tip made it so much easier. Like I never knew that about the Dash seasonings or something like thing, it might intrigue them, oh what else can I learn oh I don't know on here.

#### **3.9.10 Additional content.**

Participants felt that it was appropriate to link information with the Heart and Stroke Foundation as it provided additional information such as recipes. However, other topics to post on the website were suggested by all participants. For example, one healthcare provider felt a top ten list of the most frequently asked questions at the HFC would be of value. Another healthcare professional suggested trivia games to test knowledge such as "out of these five foods which has the most salt content." Caregivers and health care professionals agreed that it was important to provide information on current research. As discussed by one health care professional:

Sometimes there's things that come up, like things you've heard in the media, like new medications or new diets or does omega 3 really work for heart failure. There's a controversy about salt and do you really need to cut it out there's new studies that you could let them know about from a patient friendly kind of way. Things on your radar that might affect heart failure, devices, what's new in heart failure section, what's coming up.

Other topics, discussed by both caregivers and health care professionals included home care and palliative care. One health care professional suggested that it was important to bring up "the issue of palliative care sooner in heart failure."

### **3.9.11 Website approval.**

Website approval by a separate health care body such as the Health on the Net Foundation was an important consideration for one healthcare provider (Health on the Net Foundation [HON], 2014a). HON is a non-governmental agency that promotes and guides the appropriate use of health information on the Internet. As one health care professional stated,

Because when I'm looking for websites that are reputable I look for that HON thing at the bottom and then some do that too. But if the information that you find in here you can say is reputable then it just validates the website more and then more professionals might agree use it or recommend it to their caregivers and patients they're involved with.

The healthcare provider further stated, "unless this thing unless this website have this HON certificate you generally can't trust anything on the website. This is the certification that the information being presented is reputable, like Medline." However, one health professional disagreed and stated, "but as soon as it was to me it was recommended by any part of my healthcare team I'd feel it was credible without even checking it out. Does that make sense?"

### **3.9.12 Good refresher.**

Caregivers found the health information to be an excellent refresher as it kept her "on the spot." Another caregiver agreed:

I think that a lot of the benefit came from again things with practical applications right. So when we were traveling, oh yeah we should make granola bars to take instead of buying them. Stupid little things like that but they're a big deal. right. Or even just re-reading some of the basic heart failure information was again good because it was all concise. I mean it's definitely in general a good tool, I would recommend it.

One caregiver felt the information was useful and stated, "Yeah for the most part, I did like your information, and you know. I didn't find anything that I wasn't interested in. I wasn't on it all that much, because when I get home from work I'm pooped. But yeah I did go on and what I read and what I seen yeah it was useful for me." Having access to the information at any time

was also a benefit. As stated by one caregiver:

I wish I had the time to use it and post more than I did. But knowing I guess knowing that it is online I guess you wouldn't feel that pressure because it's always there. If you didn't do it this week or last week you can always do it next week or the week after. So Life is life.

Another health care professional agreed that easy access is needed and stated:

I think the knowledge that they get is – because you can go back to it and look at it again or go what was I thinking and entering something else in. If they change their mind or discovered something else that works just as good. I think that would be good.



## **CHAPTER FOUR**

### **Discussion**

The purpose of this interpretive description study was to explore the factors that have and will continue to influence or contribute to caregivers' use of social networking as a form of social support when a family member is learning to live well with heart failure. The following questions guided this interpretive description research study: How do family members and/or nonfamily members for patients with heart failure define the illness, their day-to-day situation, and social support? How do professional health care professionals define social support for caregivers of patients with heart failure? How do family members and nonfamily members manage their lives and the lives of their loved ones? Under which conditions do family member and nonfamily members for patients with heart failure use social media as a source of health information and peer support? What do family members and nonfamily members for patients with heart failure see as the consequences of using or not using online sources for information and support? What do professional health care professionals see as the consequences of using or not using online sources of information and support? An insight into the factors that contributed to the caregivers' search for online sources of health information and peer support has been gained along with identifying caregivers' and health care professionals' perceived consequences of utilizing online resources and social support. The discussion that follows is organized according to the identified factors and examines how the findings are congruent with current literature.

The Living Well with Heart Failure NING site explored how caregivers gain knowledge and social support from discussing health information online. The site was designed with the

assistance of health care professionals who reviewed the website for content and provided qualitative information on the use of online health information. Caregivers reported liking the social aspects of the site which is consistent with findings respecting other online communities such as PatientsLikeMe that self-reported improved psychological experiences of living with their chronic illnesses (Wicks et al., 2010).

#### **4.1 Participants**

In total, six caregivers participated in the research project and four completed the final interview. Originally 11 caregivers expressed interest in taking part in the study, but due to various personal circumstances, five caregivers were not able to take part in the study. Two caregivers enrolled in the project did not formally withdraw from the study; however, one caregiver was not able to complete the second interview as her husband was transferred to a long-term care facility at that time. The other caregiver did not use the website because although she owned a computer and had Internet access, she did not routinely use a computer and could not overcome this hesitation during the study. This hesitation was found in another project using an Internet-based intervention with heart transplant recipients (Dew, et al., 2004).

The ages of the caregivers reflect the ages of patients currently seeking treatment in the HFC, which currently sees patients ranging in age from 37 years to 90 years of age. All caregivers that participated in the research were female and Caucasian. Five caregivers supported their husbands, in their homes, with living well with heart failure, and one caregiver supported her father, who lived in an assisted care facility. These demographic findings are similar to other studies conducted with caregivers. Hwang et al. (2011) reported that the majority of patients diagnosed with heart failure were married men with the mean age of 53.8 years and had NYHA Class II or Class III (Hwang et al., p. 435). The primary characteristics of the caregivers were the

spouse of the patient, female, mean age of 53.4 years and currently employed full or part-time (Hwang et al., p. 436). Hwang et al. (2011) found the majority of caregivers were caring for their family member for on average 4.5 years with a range from two months to 24 years. These findings are similar to the caregivers in the current study. Three caregivers reported they were currently working full or part time and one other caregiver quit her job to care for her husband. Their husbands were self-classified at Class II or Class III.

The majority of caregivers accessed the Internet in pursuit of health information, to clarify definitions of medical terms, check email, stay connected with family and friends, do online shopping and use maps. These findings vary from other reported studies. One study found that caregivers who routinely use technology were equally divided between woman and men, who predominantly care for a female (UnitedHealthcare, 2011). Approximately half of the caregivers who used technology were under the age of 50 and the majority were caring for a parent. In this current study, all caregivers were female carrying for a male relative, typically a husband, and five of the six caregivers were over the age of 50 years.

Similar to the findings of van Uden-Kraan et al. (2010), caregivers expressed a preference for face-to-face meetings with their health care professional and used the Internet to look up health information which they could then discuss with their health care professional. The study by van Uden-Kraan et al. (2010) of patient and caregiver initiated online support groups and found that the majority of webmasters were women and ranged between 24 to 65 years of age. These webmasters started their online support groups to facilitate patients diagnosed with the same disease to "virtually meet" and share experiences. These findings were similar in this study as the greatest participation occurred between participants between approximately 35 to 65 years of age. Mase et al. (2015) found that older women with good social support were most

likely to engage in group peer support sessions. The caregivers were excited to join the research study as they felt that they had knowledge around heart failure and were willing to share their experiences with others.

Once enrolled on the Living Well with Heart Failure NING site, caregivers posted a total of 10 postings. Mase et al. (2015) discuss challenges around patient engagement in heart failure self-management studies, suggested that there is typically a low level of engagement in this group. Reasons for low and declining participation in Mase's (2015) study included comments that they "did not need or want the services, had no time, disliked telephone calls or did not need the kind of program offered" ( p. 538). Mase et al. (2015) stated that older women with a better self-reported health status, adequate social support, who demonstrated ability to manage the physical and emotional aspects of living with heart failure participated more actively in the program. In my study, all caregivers were female and focused on assisting their family member manage the physical and emotional aspects of living with heart failure, a pattern that was also reflected in a recent study by Graven & Grant (2013) which suggested that men receive more instrumental support from their spouses.

In this research study, the majority of the caregivers were not interested in a website that focused primarily on managing health or heart failure, as they felt that sufficiently informed on this subject matter. This finding at first was surprising as developing a website to help manage health was the intent of the research project. However, the caregivers stated that they were interested in sharing their experiences with others and helping others learn to live with heart failure. The issue around altruism reflected that the participants truly wanted to volunteer their time and focus on participating rather feeling obligated to participate in the project simply out of a sense of duty. All caregivers stated that they genuinely wanted to help the next caregiver.

These motives and goals were similar to the findings of van Uden-Kraan et al. (2010) who studied webmasters or those that created their own websites, where reasons for participating in an online support group focused on creating an environment where patients could meet and share experiences or empower others with the knowledge to discuss treatment plans with their physician (van Uden-Kraan). This varied from the findings of United Healthcare (2011) which found caregivers were interested in a technology that could assist with decision support tools and an interactive system for physical, mental, and leisure activities.

#### **4.2 Saskatchewan Heart Failure Network NING site**

The Saskatchewan Heart Failure Network and the Living Well with Heart Failure NING websites were designed to cater to a particular disease condition, specifically, heart failure. For research purposes, the site was created as a closed community to ensure confidentiality of the participants. In a closed community, the content is visible to community members only. Community members may add content or actively contribute to the site only after permission has been granted to access the website. The Saskatchewan Heart Failure Network NING site shared a variety of topics posted for the users along with an ability for caregivers to interact with one another in a chat room. The Saskatchewan Heart Failure Network had been set up similarly to other closed medical communities. An outpatient Parkinson Clinic has established a closed community which is accessible only to the patients using the clinic and the health care professionals who work there and facilitates communication between the two groups (van der Eijk et al., 2013). In this closed community, the Parkinson clinic had information about the clinic itself posted by the multi-disciplinary health care professionals. Similarly, the Saskatchewan Living with Heart Failure NING site is specific to the Regina Qu'Appelle Health Region but may be made generalizable to a larger community.

The health care professionals reviewed health information specifically related to heart failure and critical areas for discussion based on their experience to date working with caregivers and patients diagnosed with heart failure. The benefits of focusing the health information to a particular topic are that the website may meet the needs of those individuals at a specific moment or a specific challenge or a specific phase in their diagnosis. This may be accomplished by the use of sharing experiences with others. Colineau & Paris (2010) stated the benefits of focusing on one particular condition is that people are more likely to find someone that they can relate to due to similar experiences with a medical condition. Another benefit of a targeted community is that these sites may not have as much traffic or users as a general health site (Colineau & Paris, 2010) and thus have less information to navigate (Ma, Warren, Phillips, & Stanek, 2006). The health care professionals found the Saskatchewan Heart Failure Network NING site to be user-friendly and very relevant for the patient population due to the focused content.

The health care professionals commented positively on the topics chosen; as well as, the multiple ways of learning. The health care professionals liked the use of pictures, videos, and website links to different content. The health care professionals also liked having links to the Heart and Stroke Foundation. Including health care professionals in the development of an online health community, such as the Saskatchewan Heart Failure Network was seen as an advantage. This site is beneficial to health care professionals, patients and caregivers. The information available on the site is up to date with research and will help develop disease specific expertise relevant to the community (van der Eijk et al., 2013). Wicks et al. (2010) stated that another benefit of such participation is that patients can make better use of their time with health care professionals when they do have a face to face meeting. Wicks et al. (2010) stated that the Internet provides a platform to develop efficiently, sustainable online resources for patients to

learn about medical conditions, meet others living with the same disease, and, ultimately assume more responsibility for their health which may eventually decrease health care costs.

Health literacy also played a key role in the development of the Living Well with Heart Failure site. Healthcare professionals and caregivers commented that the site was easy to read and understand based on the choice of words. The readability of any website is an important consideration. Patient education materials are to be written at a grade three to seven reading level for the average person who reads at a grade eight level (Hansberry, Agarwal, & Baker, 2015). However, research has shown that health care professionals are designing and writing patient education materials at a higher grade level (Hansberry, Agarwal, & Baker).

#### **4.3 Defining Heart Failure**

Heart failure is defined as the impaired pumping and filling ability of the ventricles which results in the body not receiving enough blood, oxygen and nutrients (Wagner, Johnson, & Hardin-Pierce, 2010). The term previously used was congestive heart failure. The word *congestive* is no longer used as not all patients will have a fluid volume overload or pulmonary congestion (Wagner, Johnson, & Hardin-Pierce). The research study demonstrated that the caregivers had a good overall understanding of heart failure. Two caregivers described heart failure as the end result of a disease process and stated that "your heart is not working as well as it should." One caregiver said that the heart "is damaged, but it will not function the same way it used to." Another caregiver defined heart failure by the symptoms experienced by her husband. Many described it as the result of other medical conditions such as following a "heart attack" or myocardial infarction, while one stated that heart failure occurred following a stroke. In a recent report by the Heart and Stroke Foundation (2016), the general public was polled, and many Canadians were not able to define heart failure. The Heart and Stroke Foundation reported that

many Canadians thought that heart failure meant that the heart completely stopped beating, or that heart failure was something that happened as a part of natural aging. This research study has demonstrated the importance and effectiveness of educational messages related to disease conditions following discharge from the hospital.

#### **4.4 Knowledge deficit: Understanding Signs and Symptoms**

Caregivers commented that many of their daily activities included assisting with diet, ensuring that their family member takes the appropriate rest breaks, assisting with medication management and traveling to physician or HFC appointments. This activities list is supported in the literature which found that caregivers provided assistance with medications, blood pressure monitoring, dietary changes, scheduling appointments and encouraging exercise (Buck et al., 2015; Gallagher, Luttik, & Jaarsma, 2011; Luttik et al., 2007). One caregiver spoke of needing to understand the signs and symptoms experienced by her father to determine if he needs to go the hospital immediately or if it could wait until the next appointment at the HFC. Other researchers have found that caregivers describe their role as a learning process involving planning, patience, and organization (Kitko & Hupcey, 2013; Luttik et al., 2007). Caregivers described the need to continually monitor their family member and assist with such things as dietary choices and treatments. One caregiver stated she was vigilant concerning her husband's coughing and assessing each time why he is coughing. This type of symptom monitoring has been found to be common in all stages of the disease process (Kitko & Hupcey, 2013). The caregivers reported shortness of breath as a common symptom which their loved one experienced, especially orthopnea or shortness of breath when laying down which requires the use of pillows to ease breathing. These findings are reflected in the work of McMillan et al. (2013) who found common symptoms reported included shortness of breath, pain, swelling of the arms or legs, and



constipation. In addition, a decline in cognitive function is also associated with heart failure (Lam & Smeltzer, 2013) and was reported by caregivers in the current study.

One caregiver requested information related to palliative measures or knowing more about the trajectory of the disease process, exacerbation periods, or times of instability. Learning about palliative measures was supported in the literature as research has found that caregivers need more focused, situation specific information as caregivers often need to work through other sources of stress such as missed work, lost wages and increased expenses related to hospitalization (Buck et al., 2013; Harding et al., 2008; Huber, Dietrich, Cugini & Burke, 2005). Overall, online support groups help patients and caregivers to feel better informed about the disease process, assist in finding ways to live with the disease, feeling more in control and less inhibited in face to face encounters (Lemire, Sicotte, & Paré, 2008). One caregiver who did share her husband's diagnosis with friends and families was interested in face to face meetings with others following participation on the website which is supported in the literature.

#### **4.5 Changes to activity: Activity Intolerance**

Caregivers frequently discussed how changes to mobility impacted their lifestyle concerning employment status, travel, and other recreational activities. Exercise training with patients with stable New York Heart Association Class I-III is recommended (Moe et al., 2014). Patients receive printed information on exercising for 30 minutes most days of the week. Cardiac rehabilitation in a supervised setting is encouraged as patients are monitored by a physician or registered nurse. An exercise program can be developed to meet the individual needs of the patient with heart failure (Moe et al.).

There were also psychological aspects as caregivers focused on maintaining the mental health of their loved one. One caregiver stated she was careful to use the term "we" when

discussing changes in activity in order prevent their loved one from feeling like an "invalid" due to changes in lifestyle as a result of the disease process. Similarly, Kitko and Hupcey (2013) described the detailed psychological work that was involved in the caregiving role. Caregivers in both rural and urban settings in this study commented on the psychological aspects of caregiving with a focus on their loved one living with heart failure. Although the psychological aspect of the patient is necessary, caregivers need to focus on their own physical and mental well-being.

#### **4.6 Changes to Routine: Impaired Walking**

All caregivers noted that changes to their loved ones' mobility impacted their lifestyle. The patients diagnosed with heart failure were impacted financially as several commented that they were required to retire and many were impacted socially as it also required a change in recreational activities. Changes in activity levels may affect social interactions with others. It is important for caregivers to focus on their own health and well-being. Suggested activities were provided on two separate postings, however no caregivers focused on how to improve their own health or activity level.

##### **4.6.1 Travel.**

Travel was an important topic identified by health care professionals and all caregivers. The topic of travel also lead to the discussion on eating out and traveling with medical devices. All caregivers had a good understanding of the restrictions according to insurance company coverage. The majority of the caregivers commented that they no longer travel outside of Canada or prefer to stay at home. Caregivers cited reasons for this such as lack of medical coverage. Caregivers also commented that their social activities changed as they stayed closer to home. This is similar to the findings by Hwang et al. (2011) who found that caregivers felt that their

daily activities were centered on the care of their family member and that caregivers felt the need to be available 24 hours a day so gave up their social events. Caregivers commented that their day-to-day activities focused on activities such as having coffee with friends or shopping. Most of the caregivers stayed close to home to be near their family member.

#### **4.7 Source of Medical Information**

The HFC provided a source of medical information and instrumental support for the caregivers in the research study. The HFC provides educational interventions to the patients diagnosed with heart failure and their caregivers. The patients receive one-on-one didactic patient education sessions and receive teaching from the pharmacist, nurse, dietitian, and other health care professionals as required. Following the educational sessions, patients may call the HFC with any question or concern they may have related to their symptoms and treatment plan. The caregivers felt satisfied with this level of support as they knew that they could call the HFC at any time for assistance. These types of programs have demonstrated an improvement in patient knowledge as confirmed in the caregiver's knowledge related to the definition of heart failure, a low salt diet, travel restrictions due to medical coverage, and available treatment options such as the implantable cardiac defibrillator. A research study found that there are no consistent improvements in self-care abilities, quality of life and mortality with this type of educational program and programs should focus on meeting the needs and preferences of the patient (Boyde, Turner, Thompson & Stewart., 2011). The Living Well with Heart Failure NING site met the needs of the caregivers as they used the portions of the site that were of specific relevance at that moment in time. Three caregivers commented that they liked the site and wanted to continue to have access to the site after the research study was completed. The caregivers found information easy to read and easily accessible which required little other

Internet searching. One caregiver printed the information from the site for future reference.

#### **4.7.1 Paper-based information.**

For the caregivers, much of the teaching provided focused on the use of paper-based information in the form of teaching pamphlets and booklets provided from the HFC and routinely used this information when reviewing health information. The caregivers continued to use paper-based information such as articles found in magazines for health information. Two caregivers, both from rural areas, provided copies of the information furnished by the HFC. This information was close at hand, kept on a bookshelf in the kitchen or living room. Both caregivers were experienced in their role. Their spouse was diagnosed with heart failure two and half years and twelve years respectively. Both caregivers did not have access to a medical center in their community after clinic hours, with the closest physician approximately one hour from their location. Research has shown that verbal education is most frequently used in patient education and that follow-up information is provided in the form of written resources (Boyde, Turner, Thompson, & Stewart, 2011).

#### **4.7.2 Just Google it.**

Caregivers used the Internet for various activities such as checking emails, looking up information, online shopping and connecting with family and friends. Typical websites used to review health information included the Mayo Clinic and the Heart and Stroke website. Overall, the caregivers found the information on the Internet to be credible and were cautious with Internet sites selling products or requesting a chat with a medical professional. The caregivers demonstrated that they had a good understanding of reputable sources of online information. One caregiver commented that they were instructed on which Internet sites were safe to use, while

two other caregivers used websites that they commonly used while employed. Traditional sources of health information such as talking with their health care professional are still widely used and accepted, however, more people are using various sources to help them to understand health information. One study reported that all participants reported looking online for health information, while 68% continued to use face to face meetings, 50% used printed health information and 18% sought advice over the telephone (Colineau & Paris, 2013).

#### **4.8 Interest in the Use of Social Networking**

Before using the Living Well with Heart Failure NING site, the majority of caregivers stated that they were not interested in using social networking tools as a source of support or health information. This finding was interesting as half of the caregivers used social networking sites such as Facebook to stay in touch with family and friends. Online communication can be a low cost, easy to access self-help tool for older adults that allow older adults to learn at their own pace (Zach, Dalrymple, Rogers, & Williver-Farr, 2011). Online social networking tools also give caregivers access to other caregivers on a more routine basis rather than just talking with someone in a clinic office. Online social networking sites allow people to communicate with others they would otherwise not have access to or connect with to share stories and support through synchronous or asynchronous communication. However, the negative attitude towards the use of social networking was similar to another research study that showed that older adults were less positive about computers than their younger counterparts (Xie, Watkins, Golbeck & Huang, 2012). However over time the participants' views changed to more positive, engaged experiences. This finding was similar in the current research study as the caregivers began to see the benefits of use and became engaged with other caregivers. Some older adults have been noted to have concerns related to privacy (Xie, Watkins, Golbeck & Huang, 2012), though, in

this research project, the caregivers stated that they had no privacy concerns given the strategies taken to protect their identity. Despite this conjecture, privacy concerns may have played a role in the number of postings and the types of topics discussed. Caregivers focused on topics related to diet, which may have been considered safe rather than topics such as sexuality or depression.

Smith (2007) found that keeping participants coming back to a website depends heavily on the disclosure of information statement and ultimately depends on if they access websites that collect personal information (Smith). In the current study, some caregivers were open and fully disclosed information about their husband or father; while others remained closed and did not disclose information to others in the group. Dracup (2013) suggests that low participation may result from a perception of a heavy burden as a result of involvement when the caregivers and patients are required to monitor weights, salt restrictions and following medication regimen. Caregivers and patients diagnosed with a chronic illness are encouraged to visit chronic disease websites to meet others with similar medical experiences.

#### **4.9 Suggested Audience**

Caregivers felt that the Living Well with Heart Failure site would be more useful for caregivers and patients who are newly diagnosed with heart failure. This finding is similar to another research study that found that caregivers' responses to interventions are determined in part, by the length of time that they have been in the caregiver role (Buck, Zambroski, Garrison, & McMillan, 2013; Heisler et al., 2013). This same research project found that caregivers by virtue of their caregiver experience, have developed expertise in their role and as such felt offering an intervention such as learning to manage symptoms such as dyspnea, edema, pain and constipation would be more valuable to caregivers earlier in their role assumption (Buck et al.). This finding is interesting as learning can happen in all stages of the disease process as any

disease progresses or changes. At one point in time, a caregiver may feel confident in his/her skills and abilities and when presented with a new situation, may need extra encouragement and support by others who have had similar experiences.

One caregiver stated that the website would be accessed differently depending upon the needs of the individual searching for information. LaCoursiere's (2001) theory of online social support substantiates the caregivers' reasoning for use early on in the diagnosis as she states that caregivers use online supports as a way to decrease isolation and enhance decision-making skills for the caregiver. This was made evident as the caregivers shared their experiences with one another and assisted each other with tips on topics such as travel or using medication bubble packs to dispense medications.

#### **4.10 Ease of use**

All caregivers commented that the Living Well with Heart Failure NING site was easy to use. Several caregivers mentioned that they liked how easy it was to monitor activity by seeing who recently posted in the activity feed. The appearance of the website is an important consideration in the development of any site (Schneider, van Osch & de Vries, 2012). Websites should be appealing to attract visitors and keep visitors on the site. A website should have a lively appearance with the use of color and visual aids. In the development of the Living Well with Heart Failure site, these principles were taken into account. A blue background, which is highly neutral, was chosen for the website. In several of the forum postings, visual aids such as medical diagrams were used. Pictures such as hearts, exercise, and the torso, were added to draw attention or explain the text in the forum post. Another consideration for health related websites is the need to provide information on how to maintain a healthy lifestyle (Schneider, van Osch & de Vries). The caregivers had access to many forum postings on topics such as symptoms of

heart failure, a healthy diet low in salt, smoking cessation, exercise, and living well as a caregiver.

Research also shows that participants like to customize a website to meet their needs (Schneider, van Osch & de Vries, 2012). Caregivers had the opportunity to add forum topics or ask questions of each other in a caregiver group, however throughout the research study, the caregivers initiated no new topics. Caregivers added to the discussion according to their needs and responded to those items of interest, while other items had no responses such as living well as a caregiver, exercise, and losing weight.

#### **4.11 Sharing experiences- Functional support**

Caregivers enjoyed the ability to share experiences with someone else and to see how they handled various day-to-day activities. This finding was supported in the literature as a study on concussion awareness found that the majority of participants are using online support groups to relate personal experiences regarding their injuries (Ahmed, Sullivan, Schneiders & McCrory, 2010). One health care professional stated that it was similar to meeting in a waiting room. However the caregivers could access each other at any time. One research study found that online health communities connected people together who were not able to meet face to face (van der Eijk et al., 2013). Sharing experiences online also increased the social support circle as it allows individuals to extend and strengthen their networks by adding new connections (Bartlett & Coulson, 2011; Poirer & Cobb, 2012). Online social support (LaCoursiere, 2001) is the "process of initiating, participating in, and developing electronic interactions to seek beneficial outcomes in health care status, perceived health or psychosocial processing" (p. 66). The caregivers initiated conversations by first sharing information about their story with heart failure; caregivers participated in electronic interactions by discussing topics and sharing tips with one



another which benefitted the other caregivers who learned more about traveling and low salt seasoning options. The caregivers demonstrated functional support as they encouraged one another to share their experiences and encouraged the exchange of information. Peer support is valued as peers are seen as supportive and understanding of personal situations (Årestedt, Saveman, Johansson, & Blomqvist, 2013; Colineau & Paris, 2010; Trivedi, Piette, Fihn, & Edelman, 2012; van Uden-Kraan, Drossaert, Taal, Seydel, van de Laar, 2009).

#### **4.12 More of a Lurker**

The caregivers posted comments on topics such as low salt diet, traveling, and medications. In Wicks et al. (2010) found that patients engaged with their website more when they were likely to have someone they could communicate with about a particular topic. The caregivers in this research stated the same. The caregivers indicated that they enjoyed reading what other caregivers experienced and how they dealt with specific situations such as travel. Some caregivers chose not to post anything but rather read what others had to say. Four caregivers shared details about their husband's journey with heart failure. The caregivers shared details around their spouse's medical conditions and issues around day-to-day living such as how to continue with a low salt diet during travel. The caregivers stated that they felt comfortable sharing information online. LaCoursiere (2001) defines this as positive feedback phenomena. She further suggests that at various points in time an individual may be in need of more or less social support and thus may seek help and advice when it is necessary and may feel comfortable stepping back in participation or using the time to provide support to others in the group. Again, a few of the caregivers identified that they posted information to provide help and support to others because they have been through a similar situation before. Caregivers also stated that if something changed in their loved one's health, then they would return to the site to see what

other caregivers had to say. LaCoursiere labels this activity as an initiating event which occurs when an individual seeks online social support when there is an alteration in their health. Overall, the caregivers demonstrated beginning behaviors in the online social support theory. Other research studies also found that some participants chose not to participate on their site but did access to the website to read other postings (Colineau & Paris, 2010). Wicks et al. (2010) caution about widening the "digital divide" among those patients who choose to share online and those who do not. Wicks et al. found patients who find someone to discuss their situation, review new medications or other treatment plans received more benefits by participating. While Wagner, Bundorf, Singer, and Baker (2005) found just seeking information on the Internet is a potential risk if people are not able to judge the quality of information or have access to or use a computer (Cresci, Yarandi, & Morrell),2010). Health information available on the Internet can improve monitoring of disease conditions, provide access to health care professionals, reduce travel, and potentially lead to quicker medical care (Peate, 2013).

#### **4.13 Face to Face Meeting**

Although caregivers liked the ability to go online and read or share experiences with other caregivers, some of the caregivers still wanted to meet face to face with others. It has been found that some patients diagnosed with heart failure and who are registered in a clinic-based program enjoy meeting others in a face to face meeting because it gives them an opportunity to leave their home (Whitty et al., 2012). Patients found meeting had several benefits given that each had a unique understanding of their illness and its impact on day-to-day life. One caregiver commented that it was important to meet with other caregivers rather than patients for the same reason. Sharing experiences are important as it is considered two-way sharing as participants benefit from helping others and profit from the experience of others helping them (Whitty et al.).

One study found that patients and caregivers disagree about the amount of communication about a disease process and prefer to have more communication with a patient who tended not to want to discuss the issue (Fried, Bradley, O'Leary, & Byers, 2005).

#### **4.14 Increasing Awareness**

Caregivers and health care professionals both suggested ways to increase participation on the Living Well with Heart Failure NING website. Caregivers indicated a variety of recruitment strategies such as using pamphlets or cards with the website in physicians' offices or providing cards on discharge from the hospital. Other caregivers suggested strategies such as placing advertisements in local newspapers. Health care professionals suggested having search strategies in place that would allow for the Living Well with Heart Failure NING site to appear as the first option. Other online communities such as PatientsLikeMe use a variety of resources to spread information about their online group. PatientsLikeMe use search engines, paid advertisements, newspapers, referrals from users and health care professionals to inform potential new users about the group (Wicks et al., 2010). Other research projects recruited participants by advertising in the local newspaper, patient group newsletters and cardiac rehabilitation exercise classes (Kerr et al., 2008).

Other research studies have explored why there may be few participants in online health communities. For health care professionals, using online communication changes traditional health care practices. In a traditional medical setting, the patient and caregiver make an appointment, come to an office, receive medical care and teaching. In an online environment, patients and caregivers may access information at any time. Patients and caregivers are not present in the same room so cannot be assessed through traditional techniques such as auscultation, palpation, and percussion. In an online environment, the assessment must focus on

inspection or interpretation of vital signs and diagnostic tools. Using social networking tools requires an online presence and additional time to learn the technology and keep the information current, relevant, and safe. This extra time may be a barrier as it may not fit within regular clinic office hours or staffing (van der Eijk, 2013). The health care professionals in my study reported similar concerns around time management but felt that it may free up the time of the HFC staff if the site addressed common concerns that resulted in many telephone calls or increased office appointments.

Many health care professionals and caregivers felt that it was important to have a social media website focused on either a site-specific HFC. Others suggested more of a provincial focus. Geographical considerations were taken into consideration as patients and caregivers may be isolated due to the area of the province in which they reside as well as limited access to a HFC. Caregivers and health care professionals' opinion varied throughout the research. Some felt that it was important to maintain a provincial focus so that information can be geared on health programs and needs in Saskatchewan. Others felt that the social networking website should be opened to a larger group of individuals as issues are the same whether diagnosed in Canada or elsewhere. The research varies on the audience. Some websites are national or international while others have been developed specifically for a particular patient group.

#### **4.15 Need for a Moderator**

Both caregivers and health care professionals agreed that a moderator was required for these type of websites to ensure that any information posted is accurate and that the online learning environment is safe. Several research studies agree that moderators are needed for a variety of reasons to maintain the rules of the online support group, remove any abusive postings, act as a host and invite participation and support participants with technical issues

(Grau, Grajales, Gene-Badia, Siso & De Semir, 2013; van Uden-Kraan et al., 2010). The researcher assumed this role. All rules were reviewed with the caregivers before accessing the website, and posted on the forum. All caregivers received a welcome email inviting them to join the forum. The researcher also monitored all postings to ensure that the information was safe and that the caregiver provided no identifying information.

#### **4.16 More Participation**

Several caregivers commented on the need for greater involvement among members of the closed community. Caregivers felt that if more people had access to the site or that the site was an open community that they may have participated more in discussions. Some webmasters use the high number of messages as an indication of the success of the online health group (van Uden-Kraan et al., 2010). Other success factors used as indicators for keeping a group alive include starting with a small group of patients, responding to questions of participants quickly, starting new topics, providing new members with an explanation of how the open forum works (van Uden-Kraan et al.). The researcher initiated all of these activities. Throughout the project, the researcher contacted the caregivers to see if they had any questions or needed help with the site (Taylor et al., 2012). The researcher attempted to generate discussion by adding additional posts. The researcher responded to concerns. As an example, one caregiver stated that a link to a website was no longer functional, so the link was updated. The researcher attempted to generate discussion by adding additional posts and notifying the members of the new topics. Despite these attempts, no new conversations were initiated by the caregivers.

#### **4.17 Additional Content**

Both caregivers and health care professionals thought that it was important to provide

links to other websites or other health information topics in the discussion forum postings. The caregivers and healthcare professionals felt the Heart and Stroke Foundation website was credible and valuable. Some health care professionals felt that a top 10 list of frequently asked questions or trivia questions to test the knowledge of participants would increase participation and generate interest on the site. Both caregivers and healthcare professionals felt that it was important to include current research on heart failure to keep caregivers informed of what is new and what is coming up. Some research projects have found that having access to multiple health care professionals would make caregiving less burdensome as caregivers would then have access to multiple services rather than having to keep track of multiple appointments (AARP, 2016).

#### **4.18 Website approval**

One health care professional felt that it was important for the Living Well with Heart Failure NING site to have a formal certification conducted such as through HON evaluation (HON, 2014b). This certification was deemed important in order for health care professionals to know that the information available is safe and credible. Currently, any individual can set up a website and publish health information on the Internet which then becomes available to anyone accessing the site. The HON (2014b) has several principles that must be met to ensure certification. The first principle is authority and requires the authors of the website to provide their educational background or qualifications to make sure that they are experts in the field. The second principle is that the information on the website is complementary and is not intended to replace medical advice from a physician or health care professional (HON). The third principle is confidentiality. The confidential information of users must be protected (HON). The fourth principle calls for the citation of all medical resources to ensure that any information is current and up to date (HON). The next principle calls for balanced information to be presented on any

issue. Finally, the website must be transparent as the site must provide valid contact information. The developer of the site must also disclose any financial benefit received from developing the website and all advertising must be made clearly visible and separate from any content information (HON). In developing the Living Well with Heart Failure NING site, the above principles were met. Caregivers and health care professionals were informed that the NING site was developed by a registered nurse with a background in cardiology. All caregivers and health care professionals were informed that the information on the website did not replace participation in the HFC and caregivers were instructed to seek medical advice and care as needed (Appendix I). Confidentiality was maintained for all participants as each was provided with a free email address that was registered under the name of the researcher. All caregivers used pseudonyms, and all postings were monitored. All information posted on the website was referenced and developed in conjunction with health care professionals currently working in the HFC. All caregivers were provided with the researcher's contact information. No funding was received in the development of the website. One of the top rated websites on heart failure is the American Heart Association: Heart Failure was also linked to postings in my research study (Orlowski, Oermann, Shaw-Kokot, 2013).

Health literacy is an important consideration. Health literacy involves the ability to find, understand, appraise and share information in a way that may improve or maintain health (Landry, 2015). Nurses routinely assess a patient's or caregiver's readiness to learn. Nurses should educate patients and caregivers about the risks and benefits of using health information online along with the HON criteria to help patients and caregivers find trusted, relevant, expert sources of health information (Canadian Association of Schools of Nursing, 2016). Overall, the caregivers demonstrated a strong understanding of how to find credible online information and

regularly used reliable informational sites such as the Mayo Clinic or the Heart and Stroke Foundation websites.

#### **4.19 Good Refresher**

Caregivers found the site to be a good refresher for information that they had learned. It was a tool that could reinforce self-care behaviors such as living with dietary changes. The caregivers also found that having access to health information at any time was also a benefit. Research shows that there are other benefits that one can receive by using social media for health communication. As users can create and share information online, there is an ability to share and tailor the site to what is needed by participants (Moorhead et al., 2013; Whiteford & Byrne, 2015). However, there are limitations to this use as there can be a variation in the level of engagement by the user due to factors such as personality traits, age, and gender (Moorhead et al.). This finding was also evident in my research study as older participants had difficulty "finding" the site. One caregiver commented that she was only able to access the site when her daughter could show her how to use it and another caregiver attempted to bookmark the website, but the link was placed in the trash feature of the computer.

Typical topics discussed by the caregivers focused on diet specifically a low salt diet. This finding was interesting as the caregivers have access to a dietician who covers information about low salt options. Travel and exercise were additional topics of interest to the caregivers. Several caregivers discussed not being able to travel due to issues around insurance liability and thus chose to stay closer to home. It was also interesting that exercise was not discussed more among participants as they shared their experiences with fatigue and shortness of breath. Another topic of interest for many hospitalized patients is the area of sexuality. Patients may experience erectile dysfunction as a side effect of the medications they may be prescribed and may be



embarrassed to discuss sexuality with health care professionals. Caregivers did not discuss this topic. Medications were not discussed in much detail other than packaging. This lack of discussion is another interesting finding given the need to adjust dosages as part of the treatment regimen. The Living Well with Heart Failure NING site may ultimately become a good refresher for registered nurses working with a patient diagnosed with heart failure. Albert (2013) found that nurses were not adequately prepared to teach patients about heart failure. Registered nurses and other health care professionals should participate on chronic disease websites to learn more about the condition from those living with the diagnosis.

#### **4.20 Lessons Learned**

In any research project, recruiting a large enough number of participants can prove to be difficult. In this research project, health care professionals responded quickly, while recruiting caregivers became a challenge. Following ethics approval, the research posters for both healthcare professionals and caregivers were placed in the selected cardiology units in both hospital and community settings. An email was sent to the Director of Cardiosciences notifying that ethics approval had been obtained. Unit managers were then notified. An appointment was scheduled with each unit manager to review the intents of the project and to seek permission on the best location to display the posters for caregivers and health care professionals. Posters were placed in various key areas specific to the intended participant. Posters for caregivers were placed in areas with higher visibility such as patient teaching brochure areas or unit waiting rooms. Posters for healthcare professionals were placed in staff rooms or report rooms. Additionally, the researcher met with various health care professionals during the change of shift reports to review the posters and intents of the project. The health care professionals were asked to direct any questions to the researcher. The researcher made several visits to each health care

setting to verify if posters were still visible or to check to see if other posters were required. Extra posters were available so that potential participants would not have to copy the contact information. On several occasions, the researcher found the posters were taken down or missing. Each time, extra posters were then made available. Other options were explored such as placing the research poster in a picture frame to post on the bulletin board. This approach to seeking participation with the use of posters has risks as the caregiver needs to take the initiative to respond to the call and contact the researcher.

To increase interest in participation, the researcher discussed the possibility of using incentives such as monetary compensation. This discussion occurred after caregivers started showing interest in participation. This option was not chosen in order to be fair to those participants who volunteered before a monetary compensation was offered. Other steps to reduce perceived burden on potential participants steps were taken early in the research project. Caregivers were asked to participate in the online forum a minimum of ten times. This roughly equated to two to three sessions a month. The participation number was only a suggestion and not mandatory.

Research posters were also placed in both hospital and community settings to expand the potential pool of participants. By recruiting at various locations, the benefit was that the participants could reflect caregivers at different stages of the disease process such as those newly diagnosed to those starting treatment in the HFC to those living with heart failure and comfortable in their roles.

External factors may have also played a part in the number of recruited caregivers. As a caregiver, time is a factor. Caregivers may be willing to participate in the study; however, they may perceive that they do not have the time based on various demands such as the needs of their

loved one diagnosed with heart failure, the needs of other family members, or work commitments as an example. Another factor that came up in the project was a sense of altruism. The caregivers stated that they wanted to help out other caregivers. To ensure that the caregiver wanted to participate in the research project, the researcher stressed that the caregiver did not have to participate due to the feeling that they must be involved to help someone else. A final external factor that may have impacted participation is that potential caregivers may have been less familiar with the technology. Several caregivers that participated stated that they were not that experienced with the Internet and were trained on how to use the NING site.

As previously reported, the recruitment of health care professionals was not an issue in the research project. Reflecting on the success of healthcare professionals may have been due to the relationship the researcher had previously with some of the registered nurses. The researcher worked on a cardiology unit in a casual position with two registered nurses approximately 15 years before the start of the research project. The researcher left that job as a casual general duty nurse and relocated to another city in the province before returning to the RQHR four years later and taking a position outside of the Health Region. Although 15 years had passed, the researcher had previously developed a relationship with some of the staff members which may have led to interest in participation.

Issues around the use of technology became apparent when the caregivers were granted access to the Living Well with Heart Failure NING site. Two of the older caregivers had difficulty with accessing the site due to the password. These caregivers were unfamiliar with the use of capitals or the use of symbols in a password, so a new password was created for the caregivers in order to simplify access to the site. Once on the Living Well with Heart Failure NING site, these two caregivers were able to post discussions and follow information on the site.

This finding has also been reported in the literature by McColl, Rideout, Parmar and Abba-Aji (2014), who found that unfamiliarity with the use of technology is a potential barrier in the older population, and this unfamiliarity may result in loss of interest in using the application. In the Living Well with Heart Failure NING site, the caregivers did not report losing interest. Rather they enjoyed reading other caregivers' experiences as they found similarities in noted situations.

## **CHAPTER FIVE**

### **Recommendations**

Information and communications technology, such as social networking tools provide new opportunities to complement traditional health care strategies, while offering an alternative form of peer support. The results of this research study have provided additional information as to the use online sources of peer support and the value caregivers see in the use of online resources when receiving concurrent traditional resources from outpatient Heart Failure Clinics. This chapter focuses on implications for practice and concludes with recommendations for further research.

#### **5.1 Implications for Nursing Practice**

Social networking tools that allow for sharing of ideas and collaboration are being used by hospitals, healthcare professionals, patients, and caregivers. The use of social networking allows health care professionals, patients, and caregivers the mechanism to connect with each other. The impact of this knowledge sharing will potentially improve nursing practice with respect to communication, education, and skills or knowledge retention, which will ultimately improve patients' lives. Nurses will be able to connect with other nurses and share their knowledge and experiences about patient care. Nurses who may have not worked with a particular patient population group can learn from other nurses' experiences or from an interdisciplinary team whether they live in the same city or another part of the globe. The impact of this knowledge sharing will only improve nursing practice concerning communication, education and skill or knowledge retention which will ultimately improve patients' lives. Nurses participating on social networking sites will be able to share ideas, discuss research findings, and

share information learned at professional conferences which will catalyze opportunities to discuss issues related to nursing practice by those individuals who interact with the content. Nurses will ultimately be able to share their expertise and demonstrate their value to the healthcare system. Nurses should provide information about online social networking sites to caregivers and explain what benefits participation in disease-specific groups can provide.

This research study demonstrated that a social networking site developed with healthcare professionals and potential user (caregiver) recommendations is required. Incorporating feedback from health care professionals provided caregivers with the opportunity to have safe, effective, and easily accessible information approved by health care professionals in a convenient manner.

## **5.2 Implications for Regional Health Authorities**

The results of this research project have implications for Regional Health Authorities, health care professionals, as well as caregivers of patients diagnosed with heart failure. Regional health authorities may consider providing multiple forms of online health information for patients and caregivers through the use of videos, pamphlets, and peer to peer networking sites to streamline services and improve access to health information and social support. The Regina Qu'Appelle Health Region has developed a website that provides medical information to the public on a variety of health topics. Information is available in the form of educational documents prepared by various departments in the Health Region. Topics vary and include information about various medical procedures conducted in the Health Region to treatment specific discharge instruction sheets. Information is also provided on the different services offered in the Health Region, such as home care services, palliative care, and immunization programs. Links to various paper documents are also provided to help patient initiate a conversation around topics such as end of life care.

The RQHR is currently using social media tools such as Facebook, Twitter, LinkedIn, YouTube and Pinterest to share information with the public. The Facebook page and Twitter account highlight various services provided such as health line and information related to various professional services. The LinkedIn page contains information about the Health Region along with job opportunities. The RQHR should encourage health care professionals working in the region to join the site and develop professional relationships with other health care professionals to promote discussion and strengthen professional practice. The YouTube account provides information on various initiatives taken by the Health Region to streamline care. The Health Region should record patient teaching sessions for later broadcast on YouTube so that patients and caregivers can go back and review the information which will free up time spent during face to face appointments with a health care professional. While the Pinterest site promotes exercise and healthy living activities that may be done within the community. The use of these social networking tools demonstrates a strong commitment by the RQHR to communicate with the public and increase health awareness through services available in the Health Region.

The RQHR can use the findings of the research project to enhance and streamline patient services currently provided. The findings suggest that health care professionals and caregivers would like to be involved in the development of social networking tools. The results of the research provide an insight into their employees' perspectives on the use and effectiveness of online social support sites, their preferences for specific teaching tools, such as videos and website links, along with additional topics that are important to discuss during a patient's stay in hospital or following discharge. The findings suggest that health care professionals need to reflect on the possible choice of names for any developed social group so that it can clearly designate potential members, not only disease process. Any online tool developed will also have

implications related to credibility as caregivers trusted the information provided within their Health Region, rather than out of province. This finding will have implications for Health Regions considering using previously developed online tools by other Health Regions. Health Regions are encouraged to use and research the effectiveness of using social networking tools to connect health care professionals, patients, and caregivers. By using the technology, the Health Region can explore any security issues around electronic messaging between health care professionals, patients, and caregivers. Using technology will also identify if there are any differences in the level of care received when technology is used to bring health care professionals, patients, and caregivers together.

The findings also demonstrate a strong social support element in the use of social networking tools. Health Regions should explore other ways of incorporating social networking tools into their workplace. For example, nursing units may establish networks specifically for their specialty in which they could provide educational topics to maintain competency, discuss current research in their specialty areas, and provide support to new graduates or new staff members working on the unit. Developing social networking sites around a specific disease or health topics may be established so that current research, education, and social support may be focused upon and opened to any interested members. Once social networking sites are created, protocols and workshops need to be developed on professionalism related to its use or policies established around specific sites.

Clinical areas in the Health Region should consider NING to embed social networking. Patients with heart failure are often frequent users of emergency and hospital services which can present a significant burden on hospital resources. This research project has demonstrated that sharing caregivers' experiences with one another will positively reinforce self-care behaviors



related to areas such as medication compliance, exercise, and a low salt diet. By improving self-care behaviors and increasing caregivers' confidence in their abilities, this may ultimately result in lower readmission rates. Also, the next generation of caregivers and patients will be even more even more web-experienced so health care agencies will need to enhance the online social support to meet the changing needs for all people of Saskatchewan.

### **5.3 Implications for Health Care Professionals**

The findings have implications for health care professionals in their current day-to-day practice concerning patient teaching and discharge instructions. Paper-based information continues to be valued by the caregiver and should be used to reinforce information found on the Internet. Printed information is utilized by the patient and caregiver to review health topics following discharge. Written information should be made available for all patients and caregivers as it is a quick refresher on the subject. When providing written discharge instructions, patient education materials need to be written at a grade three to seven level. Registered nurses should continue to teach patients and caregivers how to access and find credible information on the Internet.

Healthcare professionals should encourage caregivers to meet in a group session or in an online forum to discuss pressing issues as it relates to different stages within the disease process such as implementing dietary changes or traveling with medical devices. Travel was considered an important topic by both caregivers and healthcare professionals. Issues around obtaining travel insurance should be freely discussed during admission or following discharge. Health care professionals should reflect on how they can address and encourage discussion around sensitive topics such as sexuality, death, and dying.

The findings also have implications related to the professional practice of the healthcare

professionals. Caregivers are seeking health information from a variety of resources such as printed information, television programs, magazines, or medical websites. It is important for healthcare professionals to be aware of what types of resources caregivers are using to seek information. Healthcare professionals may need to explore available tools to assess the credibility of online resources and incorporate how to evaluate online resources in their patient teaching. The findings also demonstrate that any recommended online tool or website must be evaluated as credible. Healthcare professionals are encouraged to use readily available online resources such as HON code guidelines to assist in determining credibility. Healthcare professionals are encouraged to moderate an online health community to ensure that information is safe and credible. Workshops need to be developed for healthcare professionals currently not using social networking to explore benefits around introducing social media into their practice. Physicians should be encouraged to participate early in the development of the online social networking site. Policies may need to be in place to define working group members' roles and responsibilities in developing and maintaining the site to ensure an interdisciplinary focus.

The findings have other implications for the health care professionals about which caregivers should be referred to an online social networking site. Consideration needs to be made on the personality type of the individual and what kind of benefit they will receive. The findings also suggest that health care professionals should reflect on the wording used when providing health teaching so that the medical condition is clearly defined and stated in a positive manner for those individuals living with a chronic disease.

Healthcare professionals are encouraged to join social networking sites with other health care professionals, patients, and caregivers. Healthcare professionals will benefit from learning more about the day-to-day challenges of caregivers and patients with heart failure. Health care

workers can help new graduates make the transition from novice to expert by discussing patient care experiences. This will ultimately contribute to the development of professional identities. Health care professionals working with other health care professionals can demonstrate their wealth of experience, knowledge, and what they can do professionally to impact the health of patients and caregivers.

#### **5.4 Implications for Caregivers**

The findings suggest that caregivers are open to sharing health information online. The findings suggest that caregivers should consider joining an online social support group early in their role as a caregiver. One of the benefits of social networking is that it can bring together people who previously may not have met due to geographical location. The results also suggest that caregivers should not feel obligated to post information as they can learn information by lurking, reflecting on, or reading the posts. Caregivers who live in a rural or urban setting will benefit from sharing information and stories. Caregivers are encouraged to consider the credibility of online resources and evaluate online resources by using tools such as the HON code. Caregivers are invited to learn about the disease process by participating in online social support groups moderated by a health care professional and track personal goals related to exercise, smoking cessation and weight-related changes.

#### **5.5 Implications for Web Developers**

The findings also have implications for moderators/web developers. The results demonstrate that any online group should be easy to navigate and provide multiple ways of learning. Those individuals moderating the discussion should consider the individual members' needs. Various privacy considerations should be taken into account. The findings demonstrate

that privacy was not a concern for caregivers; however steps need to be taken to protect each member. The results of the research findings also stressed the importance that any online social support group needs to be easily located with easily secured access. As sharing experiences were important for caregivers, an introductory post which allows members to get to know each other is needed. The findings also suggest steps required to increase participation in any online social networking site. Any moderator should consider strategies required to raise awareness about the online social support group.

As the number of people seeking medical care is rising, tools such as the Living Well with Heart Failure NING site could assist patients and caregivers early in the diagnosis and treatment plan stage. Developing and promoting a social networking site that is moderated by an health care professional ensures that medical information is current and up to date. It will allow patients and caregivers to develop a stronger understanding of their medical condition which may ultimately impact how services are provided in the Health Region. Findings of the research project suggest that the caregivers found a moderated online discussion board to be an effective way to review health topics. Topics included the signs and symptoms of worsening failure, the pathophysiology of the disease process, medications, and current treatments. Caregivers believe the opportunity to share experiences with others is a valuable tool early for those individuals early in their caregiving role. On the discussion forum, caregivers shared wisdom with each other on topics that were relevant to their needs at that time in their life such as learning more about low salt seasoning options. Overall caregivers were helpful when exchanging their experiences and providing tips on how they managed the day-to-day activities. Caregivers were also able to reflect on their health behaviors and became motivated by the other caregivers' experiences.

## **5.6 Implications for Nurse Educators**

Nurse educators working with undergraduate nursing students should integrate social networking or the creation of virtual communities in the classroom settings in all years of the program. Incorporating social media examples will help nursing students develop competent practice with searching and evaluating websites, social media sites and online support groups with respect to currency, credibility, and relevancy. It will also reinforce compliance with legal and regulatory requirements and ethical standards concerning protection of health information. For example, nursing students could discuss implications related to having the caregiver and patient data online or any effects related to receiving health information and educational support in a virtual setting or social networking community. Nursing students will also be able to explore the risks and benefits of participating in a social networking site as well as any differences in social networking sites that include healthcare professional with patients and caregivers and those without health care professionals.

## **5.7 Limitations**

As research progressed, certain challenges arose such as difficulty in recruiting caregivers. The sample size was small and recruited caregivers from one outpatient HFC in a small Western Canadian Health Region. At the beginning of the research project, the researcher and committee members did not anticipate that only a small number of caregivers would volunteer to participate in the research project. Given the researcher's previous relationship with the staff and knowledge around the number of new patients seen in the HFC each month, as well research supporting the interest of this patient population in supporting research, it was anticipated by the researcher and committee members that there would sufficient response. The reply from the health care professionals was quick and many excitedly volunteered in a short

period. It was anticipated that caregivers would be interested in participating due to increased access to health information at the time when experiencing a change in health status. Caregiver participation on the Living Well with Heart Failure NING site was limited. The researcher took measures to increase postings such as through a required minimum number of posts and added other discussion points, however these measures did not increase number of postings by the caregivers. It is also important to note that the physicians chose not to participate in the research project.

The caregivers who participated in the research project were all Caucasian females. Future studies should involve spouses and family members from varying ages, gender, and ethnic backgrounds to further understanding of how social networking tools may be used to support patients and families. The research did not compare caregivers in other HFCs across Canada, so the findings are not generalizable to a broader population. The caregivers who volunteered to be part of the study may have been highly comfortable in their role as a caregiver and as such did not require much informational support which may have impacted findings related to informational needs. There is likely a response bias as the caregivers who may have benefitted from the use of the site would be those caregivers most willing to spend their time online. The age difference between respondents is representative of the age of patients currently seen in the HFC while the number of respondents is typical to that in other research projects.

## **5.8 Recommendations for Future Research**

Future research should focus on the replication and validation of the findings from this research. The Living Well with Heart Failure NING site should be supported by Health Regions provincially to increase participation and allow for the enhancement of this social networking website to meet the needs of caregivers throughout the province. Any future research should

explore the possibility of including caregivers from other western provinces. Exploring the impact of multiple participants from multiple sites would provide insight into how peer expertise affects social support and improves medical knowledge around treatment options across the country. Additional research should be conducted on online support groups established for both patients and caregivers to determine if there are any benefits or negative consequences to group participation by caregivers and patients on the same site. Given the low response rate of caregivers, future research should explore the factors around why caregivers choose to join or not join an online health support group. Research should also explore the topics caregivers feel safe to discuss on an anonymous site with other caregivers and which issues they feel are better discussed face-to-face with a health care professional. Primary care providers should also be included in any social networking site development. Future research should focus on the primary care setting so that caregivers and patients will benefit from information earlier in the disease process and may participate in a social networking site that their primary care provider recommends. Research should also explore the use of the comprehensive guidelines by primary care providers when caring for patients diagnosed with heart failure. Overall, the research study shows great benefit for social networking and increasing social support for caregivers.

## **5.9 Knowledge Transfer**

The results of this research project will be submitted for consideration of publication in journals such as the *Canadian Journal of Cardiovascular Nursing*, the *Canadian Journal of Nursing Informatics* and journal of *Technology, Knowledge, and Society*. Abstracts will be submitted to various conferences such as the Annual Heart Failure Update by the Canadian Heart Failure Society, Nursing 2016, and the Health Care and Social Media Summit 2016. The researcher has been asked to submit an abstract on this study to the Nursing 2016 conference and

the Health Care and Social Media Summit. An abstract will also be submitted for the spring conference held by the Canadian Council of Cardiovascular Nurses. The information will also be shared using social networking tools. The results will be published on the researcher's blog and then sent out on Twitter to the researcher's followers. The researcher will also contact various organizations encouraging them to retweet the blog to their followers. The researcher will schedule a time to meet with the Director of Cardiosciences at the RQHR and the Director of Adult Medicine and Complex Care: Heart Health, Critical Care in the Saskatoon Health Region about collaborating on the site. The researcher's Living Well with Heart Failure NING site fits well with the Province of Saskatchewan's (2016) Ministry of Health performance measure for patients to access their health care professional through technology. The ultimate goal is to make the Living Well with Heart Failure NING site current and available to health care professionals, caregivers, and patients living with heart failure provincially so that it may benefit and improve the lives of the people of Saskatchewan.

## **5.10 Conclusion**

The Living Well with Heart Failure NING site demonstrated that social networking sites are a valuable tool for education and support for caregivers of patients diagnosed with heart failure. The use of social networking allows health care professionals and caregivers to connect with each other. This connection may ultimately improve nursing practice and increase knowledge sharing between health care professionals and caregivers. Caregivers of all ages are seeking health information online. Health Regions are encouraged to include healthcare professionals in the development of social networking tools. Health care professionals are the front line workers who understand the common issues and concerns of caregivers. By including health care professionals, and caregivers into social networking development, patients and



caregivers to develop a stronger understanding of their medical condition which will improve their health, treatment compliance, and social well-being.

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## Appendix A

### Recommended Initial Referral Wait Times for Patients Diagnosed with Heart Failure

Classification/Risk	Diagnosis	Recommended wait time
Routine, Elective Referral	<ul style="list-style-type: none"> <li>chronic heart failure disease management, New York Heart Association II (NYHA)</li> <li>mild to no symptoms, NYHA I</li> </ul>	<ul style="list-style-type: none"> <li>seen within 12 weeks, ideally within six weeks</li> </ul>
Semi Urgent, Intermediate Risk	<ul style="list-style-type: none"> <li>new diagnosis of heart failure, stable</li> <li>NYHA II/III</li> <li>worsening of heart failure</li> </ul>	<ul style="list-style-type: none"> <li>seen within four weeks, ideally within two weeks</li> </ul>
Urgent	<ul style="list-style-type: none"> <li>new diagnosis, not improving on therapy</li> <li>progression to NYHA IV</li> <li>post hospitalization</li> <li>Emergency room visit</li> <li>post myocardial infarction</li> </ul>	<ul style="list-style-type: none"> <li>seen in less than two weeks (Howlett et al., 2016)</li> </ul>
Emergent	<ul style="list-style-type: none"> <li>acute severe myocarditis</li> <li>cardiogenic shock</li> </ul>	

- unstable patients with transplant and device
- new onset pulmonary edema (Howlett et al., 2016)

## Appendix B

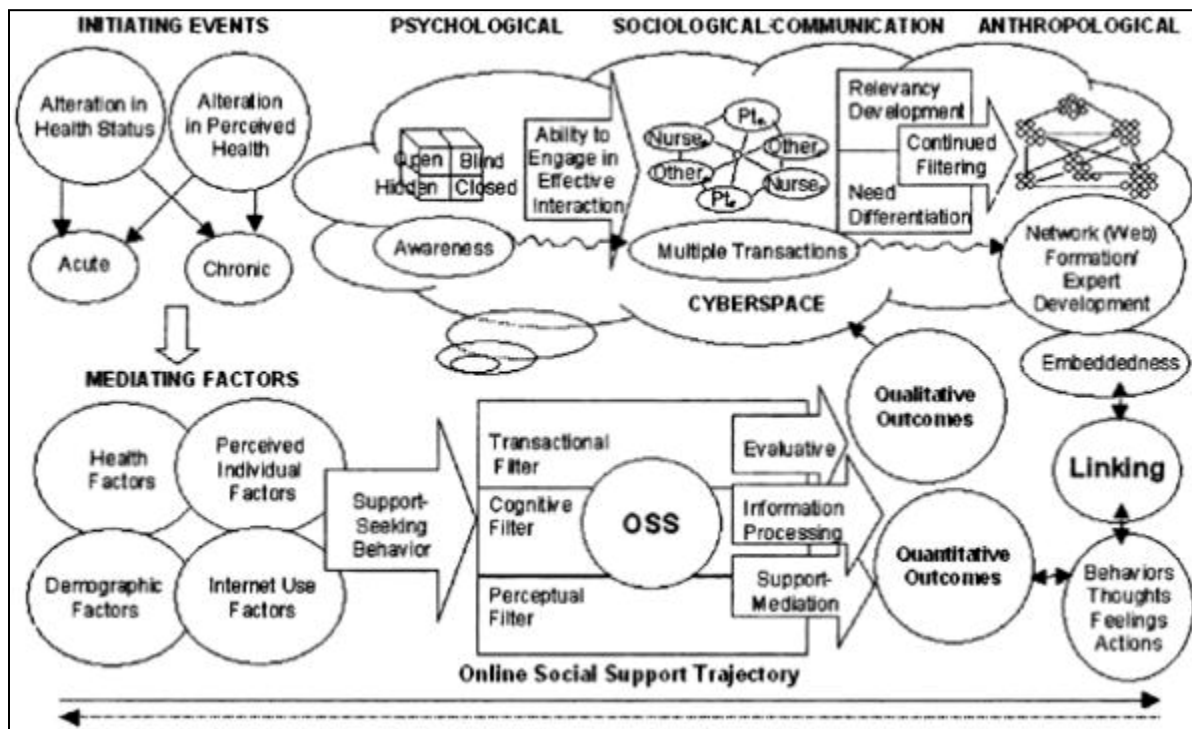
### New York Heart Association Classification

<b>Class</b>	<b>Patient Symptoms</b>
Class I (Mild)	No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, or dyspnea (shortness of breath).
Class II (Mild)	Slight limitation of physical activity. Comfortable at rest, but ordinary physical activity results in fatigue, palpitation, or dyspnea.
Class III (Moderate)	Marked limitation of physical activity. Comfortable at rest, but less than ordinary activity causes fatigue, palpitation, or dyspnea.
Class IV (Severe)	Unable to carry out any physical activity without discomfort. Symptoms of cardiac insufficiency at rest. If any physical activity is undertaken, discomfort is increased.

Heart Failure Society of America. (2002). Questions about heart failure: NYHA classification [Website]. Retrieved from [http://www.abouthf.org/questions\\_stages.htm](http://www.abouthf.org/questions_stages.htm)

## Appendix C

A Diagram of the theory of online social support



LaCoursiere, S. (2001). A theory of online social support. *Advances in Nursing Science*, 24(1), 60-77.

## Appendix D

Sample Poster Requesting Study Participation by Health Care Professional

College of Nursing  
University of Saskatchewan



### HEALTH CARE PROFESSIONALS NEEDED FOR RESEARCH IN ONLINE SOCIAL SUPPORT

I am looking for volunteers to take part in a study of online social support for caregivers of patients with heart failure.

As a participant in this study, you would be asked to: review a website and participate in a review session

Your participation would involve 2 sessions,  
each of which is approximately 90 minutes.

For more information about this study, or to volunteer for this study,  
please contact:

*Dr. Sandra Bassendowski, Professor, College of Nursing*

306-337-3810

Email: [s.bassendowski@usask.ca](mailto:s.bassendowski@usask.ca)

*PhD student, College of Nursing*

306-337-2136

[jana.davies@usask.ca](mailto:jana.davies@usask.ca)

**Reviewed by, and received approval**

**through, the Research Ethics Office, University of Saskatchewan,**

**University of Regina and the Regina Qu'Appelle Health Region**

**If you have any questions, please contact the Behavioural Ethics Research  
Office at 306.966.2975**



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## Appendix E

### Sample Poster Requesting Caregiver Participation

College of Nursing  
University of Saskatchewan



#### PARTICIPANTS NEEDED FOR RESEARCH IN ONLINE SOCIAL SUPPORT

I am looking for volunteers to take part in a study of online social support for caregivers of patients with heart failure.

As a participant in this study, you would be asked to: participate on a website with other caregivers by sharing your personal experiences with heart failure and participate in a short interview

Your participation would involve posting 10 times on a website, and 2 interviews each of which is approximately 30 minutes. You would have to have access to the Internet and a computer device.

For more information about this study, or to volunteer for this study, please contact:

*Dr. Sandra Bassendowski, Professor, College of Nursing*

306-337-3810

Email: [s.bassendowski@usask.ca](mailto:s.bassendowski@usask.ca)

*Shauna Davies, RN, MN, PhD student, College of Nursing*

306-337-2136

Email: [shauna.davies@usask.ca](mailto:shauna.davies@usask.ca)

**This study has been reviewed by, and received approval through, the Research Ethics Office, University of Saskatchewan.**

**If you have any questions please contact the Behavioural Ethics Research Office at 306.966.2975**



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**Appendix F**  
Consent for Participation for Focus Group.



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***Participant Consent Form: Focus Group -  
Health Care Professional***

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**Project Title:** Online Social Support in the Saskatchewan Heart Failure Network:  
An Interpretive Description Approach

**Researcher(s):** Shauna Davies, RN, MN, PhD(c), Graduate Student, College of Nursing,  
University of Saskatchewan, 306-337-2136, shauna.davies@usask.ca

**Supervisor:** Dr. Sandra Bassendowski, College of Nursing, 306-337-3810,  
sandra.bassendowski@usask.ca

**Purpose(s) and Objective(s) of the Research:**

- This study will use the research method of interpretive description which is a study that appreciates the experiences of others and examines how those experiences have been formed and influenced by our values, traditions, beliefs, attitudes, along with our roles and identities with others in our lives.
- The purpose of this interpretive description study is to develop an online heart failure education and support website for caregivers helping a loved one live with heart failure. This research will look at how sharing experiences and health information with another caregiver may help each caregiver individually to deal with their situation. The research will also seek to understand why it is important to find another caregiver living with a similar experience that will share their experiences and what they have learned in an online environment. The research will seek to understand if there are any good or bad consequences of looking for online health information. Over time, the study may help develop a model of online heart failure education and social support for heart failure clinics nationally.
- This interpretive description research study is guided by the following research questions: How do caregivers helping their loved ones live with heart failure define heart failure, what happens in their day-to-day life in learning to live with heart failure, and who do they seek out to talk to about any questions, concerns or issues that come up when living with heart failure? How do they manage their own lives and have time to help their loved ones living with heart failure? Will using an online chat room help care givers find out more information about heart failure? Will an online environment help a caregiver to find another person who can answer any questions and help out when any concerns arise? Are there any consequences of using online sources for information and support? This research study will potentially provide insights into the search for online sources of health information and peer support, as well as identify caregivers' perceived consequences of online social support.

**Procedures:**

- Each health care professional will be asked to participate in two focus group sessions approximately six months apart. During the focus group sessions, health care professionals will be asked to review a social networking site on health education related to congestive heart failure and express their feelings and provide feedback on the Saskatchewan Heart Failure Network. Health care professionals who do not feel open to answer questions in a public setting may respond in writing on the question sheets provided.
- Each participant will access the Saskatchewan Heart Failure Network website and will individually evaluate the content. Changes will be made to the website based on the information provided by the health care professionals prior to caregiver access.
- Each session will be audio-recorded and transcribed by the researcher. Each session will last approximately 90 minutes and will be held in a meeting room within the Regina Qu'Appelle Health Region.
- Please feel free to ask any questions regarding the procedures and goals of the study or your role.

**Potential Risks:**

- There are no known risks.

**Potential Benefits:**

- The development of a model of online heart failure education and social support that may be implemented at heart failure clinics nationally.

**Confidentiality:**

- There is a minimal potential risk to you by participating in this research given the small number of participants all known to each other.
- **Risk(s) will be addressed by:** the researcher undertaking to safeguard the confidentiality of the discussion, but cannot guarantee that other members of the group will do so. Please respect the confidentiality of the other members of the group by not disclosing the contents of this discussion outside the group, and be aware that others may not respect your confidentiality. Please follow the ethical guidelines of your professional organization with respect to confidentiality, especially in issues such as identifiable patient information or professional practice.

**Storage of Data:**

- Consent forms signed by participants, audio recordings, and transcripts from focus groups sessions will be stored separately in a locked cabinets by the researcher for a minimum period of seven years post publication. Consent forms and lists of any identifiable information will be stored separately from the data collected.
- A master list of participants will be stored in a locked cabinet by the researcher for a minimum of six months. The master list will be destroyed when data collection is complete and the master list is no longer required by the researcher. This information will be confidentially shredded. Information stored electronically will be electronically wiped.
- After a minimum period of seven years post publication, when the data is no longer required, the data will be destroyed. Information stored will be shredded or electronically

wiped. All information on the Saskatchewan Heart Failure Network will be destroyed by asking NING to delete the network.

- Data collected will be used in the researcher's dissertation with the College of Nursing, University of Saskatchewan to meet partial requirements for doctorate of philosophy in nursing. All information will be anonymized in the presentation of the data and will not be connected to you or any other specific participant.
- Data will be presented in the form of peer-reviewed research articles or at conferences provincially, nationally, or internationally.

#### **Right to Withdraw:**

- Your participation is voluntary and you can answer only those questions that you are comfortable with. You may withdraw from the research project for any reason, at any time without explanation or penalty of any sort.
- Whether you choose to participate or not will have no effect on your employment or how you will be treated.
- Should you wish to withdraw, your right to withdraw data from the study will apply before the first focus group session or before the second focus group session. As participation involves a focus group data in which has been pooled, after the focus group session, it will not be possible to withdraw your data.

#### **Follow up:**

- To obtain results from the study, please email the researcher at [shauna.davies@usask.ca](mailto:shauna.davies@usask.ca) and an electronic copy of a summary of the findings will be provided.

#### **Questions or Concerns:**

- Contact the researcher using the information at the top of first page;
- This research project has been approved on ethical grounds by the University of Saskatchewan Behavioral Research Ethics Board, The University of Regina Research Ethics Board and The Regina Qu'Appelle Health Region Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office [ethics.office@usask.ca](mailto:ethics.office@usask.ca) (306) 966-2975. Out of town participants may call toll free (888) 966-2975.

#### **Consent**

- Please put a check mark on the corresponding line that grants me permission to:

I grant permission to be audio taped: Yes: \_\_\_\_ No: \_\_\_\_

## SIGNED CONSENT

Your signature below indicates that you have read and understand the description provided; I have had an opportunity to ask questions and my/our questions have been answered. I consent to participate in the first focus group. A copy of this Consent Form has been given to me for my records.

_____ <i>Name of Participant</i>	_____ <i>Signature</i>	_____ <i>Date</i>
_____ <i>Researcher's Signature</i>	_____ <i>Date</i>	

***A copy of this consent will be left with you, and a copy will be taken by the researcher.***

**Appendix G**  
Consent for Caregiver Participation for Website and Interview



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*Participant Consent Form : Caregiver*

---

**Project Title:** Online Social Support in the Saskatchewan Heart Failure Network:  
An Interpretive Description Approach

**Researcher(s):** Shauna Davies, RN, MN, PhD(c), Graduate Student, College of Nursing,  
University of Saskatchewan, 306-337-2136, [shauna.davies@usask.ca](mailto:shauna.davies@usask.ca)

**Supervisor:** Dr. Sandra Bassendowski, College of Nursing, 306-337-3810,  
[sandra.bassendowski@usask.ca](mailto:sandra.bassendowski@usask.ca)

**Purpose(s) and Objective(s) of the Research:**

- This study will use the research method of interpretive description which is a study that appreciates the experiences of others and examines how those experiences have been formed and influenced by our values, traditions, beliefs, attitudes, along with our roles and identities with others in our lives.
- The purpose of this interpretive description study is to develop an online heart failure education and support website for caregivers helping a loved one live with heart failure. This research will look at how sharing experiences and health information with another caregiver may help each caregiver individually to deal with their situation. The research will also seek to understand why it is important to find another caregiver living with a similar experience that will share their experiences and what they have learned in an online environment. The research will seek to understand if there are any good or bad consequences of looking for online health information. Over time, the study may help to develop a model of online heart failure education and social support for heart failure clinics nationally.
- This interpretive description research study is guided by the following research questions: How do caregivers helping their loved ones live with heart failure define heart failure, what happens in their day-to-day life in learning to live with heart failure, and who do they seek out to talk to about any questions, concerns or issues that come up when living with heart failure? How do they manage their own lives and have time to help their loved ones living with heart failure? Will using an online chat room help caregivers find out more information about heart failure? Will an online environment help a caregiver to find another person who can answer any questions and help out when any concerns arise? Are there any consequences of using online sources for information and support? This research study will potentially provide insights into the search for online sources of health information and peer support, as well as identify caregivers' perceived consequences of online social support.

**Procedures:**

- You will be asked to participate in an online support group. You will need to use your own computer that connects to the internet. A new email address will be provided along with a user name, password and pseudonym which will be used to access a social media site with information on heart failure.
- We are looking for caregivers to read messages left by the researcher or other members, ask any questions you may have about congestive heart failure to other people living with heart failure, and share your stories, experiences or helpful tips if you feel comfortable sharing these on the website.
- You will be asked to ask a question or respond to a posting a minimum of ten (10) times.
- Only other caregivers who have volunteered to participate in the research study and the researcher will have access the website.
- The researcher will access the website to monitor postings and to ensure accuracy of the information provided.
- Please feel free to ask any questions regarding the procedures and goals of the study or your role by emailing the researcher or by looking at the frequently asked questions on the website.
- Following your participation on the website, you will be asked to participate in two personal/individual interviews approximately 30 minutes in length to share your experiences on the website. Each session will be audio-recorded and transcribed by the researcher and will be held in a meeting room within the Regina Qu'Appelle Health Region or a location of your choice.

**Potential Risks:**

- There are no known physical, psychological, social, or economic risks to participating in this research study.
- There may be a risk for feelings to be hurt when participating online. We ask each participant to remain polite in your response as words can be misinterpreted when reading. Please do not use all CAPITAL letters as this is the same as shouting in the Internet. Please be forgiving with postings especially when there may be a spelling mistake or a question that you may think is silly as all questions are good questions. Please be respectful in your postings.
- Please do not identify yourself, any family members, or provide information that others may identify you with such as age, birthday, employment history or place of residence etc.
- Risk(s) will be addressed by researcher: The researcher will be reading postings and approving the posts. Any post that may identify a participant or family member or is deemed as hurtful or impolite will not appear on the site. All posts must be approved by the researcher. The posts will not be altered but if any concerns arise they will not be posted.
- If you have any concerns or questions about what you have read or how information was responded to, please email the researcher and a referral back to the heart failure clinic may be offered or further information may be provided by the researcher.
- Participation in the study may be terminated if you are not courteous or respectful in your postings.

**Potential Benefits:**

- You will have access to a website on that contains current and correct heart failure health information that will be monitored by a registered nurse.
- You will be able to discuss your situation with other caregivers living with a family member with heart failure.
- You may gain increased knowledge about heart failure health education.
- The information you provide will help further develop a website that can be used by caregivers nationally.
- You may feel more empowered through having access to information – perhaps better preparing you to ask questions at future appointments or in interactions with the care team.

**Confidentiality:**

- Participation is voluntary. The participant may choose to no longer remain in the study at any time. If the participant chooses to leave the study, this withdrawal will not affect the family member's access to, or continuation of services provided by the Congestive Heart Failure Clinic at the Regina Qu'Appelle Health Region.
- When a participant chooses to leave the study, any information collected to this point will be included in the researcher's analysis as each additional posting will continue the discussion.
- Because the participants for this research project have been selected from a small group of people, it is possible that you may be identifiable to other people on the basis of what you have said.
- There are several options for you to consider if you decide to take part in this research. You can choose all, some or none of them. Please put a check mark on the corresponding lines that grants me permission to:

I wish to remain anonymous, but you may refer to me by a pseudonym (an alternate name):

Yes: \_\_\_\_ No: \_\_\_\_

The pseudonym I choose for myself is:

\_\_\_\_\_

You may quote me, using only the pseudonym that I have chosen or that has been assigned to me: Yes: \_\_\_\_ No: \_\_\_\_

**Storage of Data:**

- Consent forms signed by participants, audio recordings, and transcripts from interviews will be stored separately in a locked cabinets by the researcher for a minimum period of seven years post publication. Consent forms and lists of any identifiable information will be stored separately from the data collected.
- A master list of participants will be stored in a locked cabinet by the researcher for a minimum of six months. The master list will be destroyed when data collection is complete and the master list is no longer required by the researcher. This information will

- be confidentially shredded. Information stored electronically will be electronically wiped.
- After a minimum period of seven years post publication, when the data is no longer required, the data will be destroyed. Information stored will be shredded or electronically wiped. All information on the Saskatchewan Heart Failure Network will be destroyed by asking NING to delete the network.
- Data collected will be used in the researcher's dissertation with the College of Nursing, University of Saskatchewan to meet partial requirements for doctorate of philosophy in nursing. All information will be anonymized in the presentation of the data and will not be connected to you or any other specific participant.
- Data will be presented in the form of peer-reviewed research articles or at conferences provincially, nationally, or internationally.

#### **Right to Withdraw:**

- Your participation is voluntary and you can post questions, stories or tips about living with heart failure and answer only those questions or share information that you are comfortable with. You may withdraw from the research project for any reason, at any time without explanation or penalty of any sort.
- Whether you choose to participate or not will have no effect on your access to services by the Congestive Heart Failure Clinic or how you will be treated by the clinic or by your doctor.
- Due to the structure of the website, even if you withdraw from the study, your information, stories, or postings up to that date cannot be deleted and may continue to be part of the other members' discussion.

#### **Follow up:**

- If you would like to receive information about any presentations or copies of the papers submitted for publication, please email the researcher at [shauna.davies@usask.ca](mailto:shauna.davies@usask.ca) to receive a paper or electronic copy.

#### **Questions or Concerns:**

- Contact the researcher(s) using the information at the top of page 1;
- This research project has been approved on ethical grounds by the University of Saskatchewan Behavioral Research Ethics Board, The University of Regina Research Ethics Board, and the Regina Qu'Appelle Health Region Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office [ethics.office@usask.ca](mailto:ethics.office@usask.ca) (306) 966-2975. Out of town participants may call toll free (888) 966-2975.



## **Consent**

### **SIGNED CONSENT**

Your signature below indicates that you have read and understand the description provided. I have had an opportunity to ask questions and my/our questions have been answered. I consent to participate in the research project. A copy of this Consent Form has been given to me for my records.

_____	_____	_____
<i>Name of Participant</i>	<i>Signature</i>	<i>Date</i>

_____	_____
<i>Researcher's Signature</i>	<i>Date</i>

***A copy of this consent will be left with you when we meet to sign the form, and a copy will be taken by the researcher.***

## Appendix H

### Amended Ethics Application for Caregivers



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### *Participant Consent Form : Caregiver*

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**Project Title:** Online Social Support in the Saskatchewan Heart Failure Network: An Interpretive Description Approach

**Researcher(s):** Shauna Davies, RN, MN, PhD(c), Graduate Student, College of Nursing, University of Saskatchewan, 306-337-2136, shauna.davies@usask.ca

**Supervisor:** Dr. Sandra Bassendowski, College of Nursing, 306-337-3810, sandra.bassendowski@usask.ca

**Purpose(s) and Objective(s) of the Research:**

- This study will use the research method of interpretive description which is a study that appreciates the experiences of others and examines how those experiences have been formed and influenced by our values, traditions, beliefs, attitudes, along with our roles and identities with others in our lives.
- The purpose of this interpretive description study is to develop an online heart failure education and support website for caregivers helping a loved one live with heart failure. This research will look at how sharing experiences and health information with another caregiver may help each caregiver individually to deal with their situation. The research will also seek to understand why it is important to find another caregiver living with a similar experience that will share their experiences and what they have learned in an online environment. The research will seek to understand if there are any good or bad consequences of looking for online health information. Over time, the study may help to develop a model of online heart failure education and social support for heart failure clinics nationally.
- This interpretive description research study is guided by the following research questions: How do caregivers helping their loved ones live with heart failure define heart failure, what happens in their day-to-day life in learning to live with heart failure, and who do they seek out to talk to about any questions, concerns or issues that come up when living with heart failure? How do they manage their own lives and have time to help their loved ones living with heart failure? Will using an online chat room help care givers find out more information about heart failure? Will an online environment help a caregiver to find another person who can answer any questions and help out when any concerns arise? Are there any consequences of using online sources for information and support? This research study will potentially provide insights into the search for online sources of health information and peer support, as well as identify caregivers' perceived consequences of online social support.

**Procedures:**

- You will be asked to participate in an online support group. You will need to use your own computer that connects to the internet. You will use the email address provided along with the user name, password and pseudonym which will be used to access a social media site with information on heart failure.
- We are looking for caregivers to read messages left by the researcher or other members, ask any questions you may have about congestive heart failure to other caregivers living with heart failure, and share your stories, experiences or helpful tips if you feel comfortable sharing these on the website.
- You will be asked to ask a question or respond to a posting a minimum of ten (10) times.
- Only other caregivers who have volunteered to participate in the research study and the researcher will have access the website.
- The researcher will access the website to monitor postings and to ensure accuracy of the information provided.
- Please feel free to ask any questions regarding the procedures and goals of the study or your role by emailing the researcher or by looking at the frequently asked questions on the website.
- Following your participation on the website, you will be asked to participate in two personal/individual interviews approximately 30 minutes in length to share your experiences on the website. Each session will be audio-recorded and transcribed by the researcher and will be held in a meeting room within the Regina Qu'Appelle Health Region or a location of your choice. The tape recorder will be turned off at any time at the request of the participant.

**Potential Risks:**

- There are no known physical, psychological, social, or economic risks to participating in this research study.
- There may be a risk for feelings to be hurt when participating online. We ask each participant to remain polite in your response as words can be misinterpreted when reading. Please do not use all CAPITAL letters as this is the same as shouting in the Internet. Please be forgiving with postings especially when there may be a spelling mistake or a question that you may think is silly as all questions are good questions. Please be respectful in your postings.
- Please do not identify yourself, any family members, or provide information that others may identify you with such as age, birthday, employment history or place of residence etc.
- Risk(s) will be addressed by researcher: The researcher will be reading postings and approving the posts. Any post that may identify a participant or family member or is deemed as hurtful or impolite will not appear on the site. All posts must be approved by the researcher. The posts will not be altered but if any concerns arise they will not be posted.
- If you have any concerns or questions about what you have read or how information was responded to, please email the researcher and a referral back to the heart failure clinic may be offered or further information may be provided by the researcher.
- Participation in the study may be terminated if you are not courteous or respectful in your

postings.

**Potential Benefits:**

- You will have access to a website on that contains current and correct heart failure health information that will be monitored by a registered nurse.
- You will be able to discuss your situation with other caregivers living with a family member with heart failure.
- You may gain increased knowledge about heart failure health education.
- The information you provide will help further develop a website that can be used by caregivers nationally.
- You may feel more empowered through having access to information – perhaps better preparing you to ask questions at future appointments or in interactions with the care team.

**Confidentiality:**

- Participation is voluntary. The participant may choose to no longer remain in the study at any time. If the participant chooses to leave the study, this withdrawal will not affect the family member's access to, or continuation of services provided by the Congestive Heart Failure Clinic at the Regina Qu'Appelle Health Region.
- When a participant chooses to leave the study, any information collected to this point will be included in the researcher's analysis as each additional posting will continue the discussion.
- Because the participants for this research project have been selected from a small group of people, it is possible that you may be identifiable to other people on the basis of what you have said.
- There are several options for you to consider if you decide to take part in this research. You can choose all, some or none of them. Please put a check mark on the corresponding lines that grants me permission to:

I wish to remain anonymous, but you may refer to me by a pseudonym as chosen earlier (an alternate name):

Yes: \_\_\_\_ No: \_\_\_\_

The pseudonym I chose for myself was:

\_\_\_\_\_

You may quote me, using only the pseudonym that I have chosen or that has been assigned to me: Yes: \_\_\_\_ No: \_\_\_\_

**Storage of Data:**

- Consent forms signed by participants, audio recordings, and transcripts from interviews will be stored separately in a locked cabinets by the researcher for a minimum period of seven years post publication. Consent forms and lists of any identifiable information will be stored separately from the data collected.
- A master list of participants will be stored in a locked cabinet by the researcher for a

minimum of six months. The master list will be destroyed when data collection is complete and the master list is no longer required by the researcher. This information will be confidentially shredded. Information stored electronically will be electronically wiped.

- After a minimum period of seven years post publication, when the data is no longer required, the data will be destroyed. Information stored will be shredded or electronically wiped. All information on the Saskatchewan Heart Failure Network will be destroyed by asking NING to delete the network.
- Data collected will be used in the researcher's dissertation with the College of Nursing, University of Saskatchewan to meet partial requirements for doctorate of philosophy in nursing. All information will be anonymized in the presentation of the data and will not be connected to you or any other specific participant.
- Data will be presented in the form of peer-reviewed research articles or at conferences provincially, nationally, or internationally.

#### **Right to Withdraw:**

- Your participation is voluntary and you can post questions, stories or tips about living with heart failure and answer only those questions or share information that you are comfortable with. You may withdraw from the research project for any reason, at any time without explanation or penalty of any sort.
- Whether you choose to participate or not will have no effect on your access to services by the Congestive Heart Failure Clinic or how you will be treated by the clinic or by your doctor.
- Due to the structure of the website, even if you withdraw from the study, your information, stories, or postings up to that date cannot be deleted and may continue to be part of the other members' discussion.

#### **Follow up:**

- If you would like to receive information about any presentations or copies of the papers submitted for publication, please email the researcher at [shauna.davies@usask.ca](mailto:shauna.davies@usask.ca) to receive a paper or electronic copy.

#### **Questions or Concerns:**

- Contact the researcher(s) using the information at the top of page 1;
- This research project has been approved on ethical grounds by the University of Saskatchewan Behavioral Research Ethics Board, The University of Regina Research Ethics Board, and the Regina Qu'Appelle Health Region Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office [ethics.office@usask.ca](mailto:ethics.office@usask.ca) (306) 966-2975. Out of town participants may call toll free (888) 966-2975.

## **Consent**

### **SIGNED CONSENT**

Your signature below indicates that you have read and understand the description provided. I have had an opportunity to ask questions and my/our questions have been answered. I consent to participate in the research project. A copy of this Consent Form has been given to me for my records.

_____	_____	_____
<i>Name of Participant</i>	<i>Signature</i>	<i>Date</i>

_____	_____
<i>Researcher's Signature</i>	<i>Date</i>

***A copy of this consent will be left with you when we meet to sign the form, and a copy will be taken by the researcher.***

## Appendix I

### Waiver of Liability for Caregivers

I understand that I will be participating in a social networking website with other people living with a family member with heart failure. I understand that the researcher is not responsible for medical information posted by the members on the social networking site. If I have any questions or concerns about my health or well being, or the health and wellbeing of my family member/friend, my medical condition, treatment plan or a change in treatment plan I will contact my doctor or the Congestive Heart Failure Clinic or seek emergency treatment at the nearest hospital immediately.

Participant's Name (print): \_\_\_\_\_

Participant's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**Participant's contact Information:**

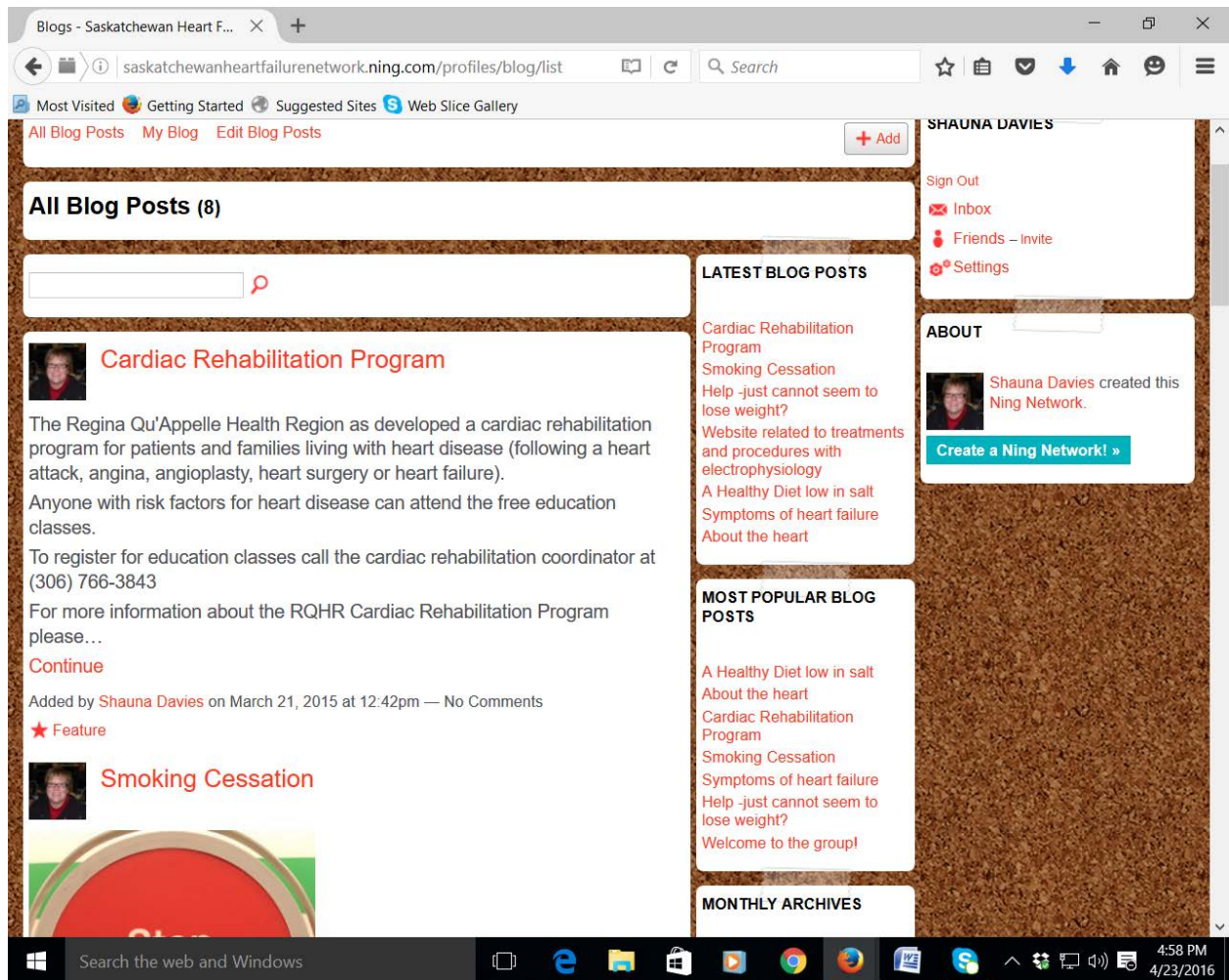
Email:

Address:

Phone:

## Appendix J

### Saskatchewan Heart Failure Network





Blogs - Saskatchewan Heart F... X +


saskatchewanheartfailurenetwork.ning.com/profiles/blog/list


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**Continue**

Added by **Shauna Davies** on March 21, 2015 at 12:42pm — No Comments

★ Feature

 **Smoking Cessation**



 by **mag3737**


You have heard from a doctor or nurse that is important to stop smoking, but why?

Nicotine causes blood vessels to tighten (or constrict) which causes...

**Continue**

Added by **Shauna Davies** on November 19, 2011 at 1:24pm — 1 Comment

★ Feature

 **Help -just cannot seem to lose weight?**

Losing weight can be difficult and you will hear from some to eat less calories

**A Healthy Diet low in salt**  
**About the heart**  
**Cardiac Rehabilitation Program**  
**Smoking Cessation**  
**Symptoms of heart failure**  
**Help -just cannot seem to lose weight?**  
**Welcome to the group!**

**MONTHLY ARCHIVES**

**2015**  
**March** (1)

**2011**  
**November** (3)  
**October** (4)

Search the web and Windows

4:58 PM  
4/23/2016


Blogs - Saskatchewan Heart F... X +

saskatchewanheartfailurenetwork.ning.com/profiles/blog/list

Most Visited Getting Started Suggested Sites Web Slice Gallery

Added by **Shauna Davies** on November 19, 2011 at 1:24pm — 1 Comment

★ Feature

 **Help -just cannot seem to lose weight?**

Losing weight can be difficult and you will hear from some to eat less calories or add additional activity to your day. So what are some tips that you can share with others to achieve more activity by making it a fun part of you day?


For me, my favorite way is to park a little farther from the store. This not only helps by adding a few extra steps, it also can make it easier to get into and out of the car if you are not squeezed into a space.

Sometimes I also do not...

[Continue](#)

Added by **Shauna Davies** on November 15, 2011 at 9:00pm — 1 Comment

★ Feature


 **Website related to treatments and procedures with electrophysiology**

Do you have questions about heart health? Maybe a question about your diagnosis and want to see an illustration or video about a specific topic then you may want to check out the following website:

[Cardiovascular media library](#)

Added by **Shauna Davies** on November 8, 2011 at 8:59pm — No Comments

★ Feature

 **A Healthy Diet low in salt**

It is important to follow a balanced diet by following [Canada's food guidelines](#).

Search the web and Windows

4:58 PM 4/23/2016




Blogs - Saskatchewan Heart F... X +

saskatchewanheartfailurenetwork.ning.com/profiles/blog/list

Most Visited Getting Started Suggested Sites Web Slice Gallery

Added by **Shauna Davies** on November 8, 2011 at 8:59pm — No Comments

★ Feature

 **A Healthy Diet low in salt**


It is important to follow a balanced diet by following **Canada's food guidelines**. Please click on the Canada's food guidelines in the previous sentence to download a copy in one of 12 languages (including French and English )from Health Canada.

Some people with heart failure may find it hard to keep a health weight because of higher energy needs, poor appetite, nausea...

[Continue](#)

Added by **Shauna Davies** on October 30, 2011 at 11:00am — 1 Comment

★ Feature

 **Symptoms of heart failure**

**Heart failure symptoms:**


Because of heart failure, your heart pumps less blood to the body. The kidneys do not get enough blood and they start to not work right. This leads to fluid backing up in the lungs and throughout your body:

- So your lungs may fill up with fluid and this will make you short of breath.
- As the kidneys cannot get rid of extra fluid, this fluid collects leading to swelling
- Swelling can be seen in your hands, abdomen or...

[Continue](#)

Added by **Shauna Davies** on October 30, 2011 at 10:30am — No Comments

★ Feature

 **About the heart**

Search the web and Windows

4:58 PM 4/23/2016

Blogs - Saskatchewan Heart F... X +

saskatchewanheartfailurenetwork.ning.com/profiles/blog/list


Search

Most Visited

Getting Started

Suggested Sites

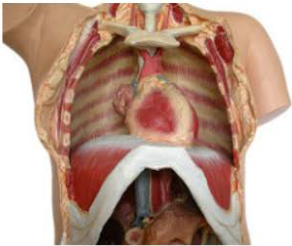
Web Slice Gallery




About the heart

The Heart

Your heart is a muscle about the size of your fist. It is located in the middle of your chest.




 by ...


Continue


Added by **Shauna Davies** on October 30, 2011 at 10:00am — No Comments

★ Feature




Welcome to the group!





Search the web and Windows



4:58 PM  
4/23/2016

154



Blogs - Saskatchewan Heart F... X +

saskatchewanheartfailurenetwork.ning.com/profiles/blog/list

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## Symptoms of heart failure

**Heart failure symptoms:**

Because of heart failure, your heart pumps less blood to the body. The kidneys do not get enough blood and they start to not work right. This leads to fluid backing up in the lungs and throughout your body:

- So your lungs may fill up with fluid and this will make you short of breath.
- As the kidneys cannot get rid of extra fluid, this fluid collects leading to swelling
- Swelling can be seen in your hands, abdomen or...

[Continue](#)


Added by **Shauna Davies** on October 30, 2011 at 10:30am — No Comments

★ Feature

## About the heart

### The Heart

Your heart is a muscle about the size of your fist. It is located in the middle of your chest.



## **Appendix K**

### **Focus Group Question Guide**

1. How interested are you in a website that helps people manage their health?
2. How often do patients and caregivers use the internet to look up health information?
3. What type of information do you think is most important to include on a social networking site on heart failure?
4. What types of information resources do patients and caregivers use to find information on congestive heart failure?
5. Are there information resources about heart failure that patients and caregivers need access to that is currently not available on this site?
6. Is the information on the social networking site easy to read and understand?
7. Would you recommend using a social networking site to patients and caregivers with whom you work? What would encourage (discourage) you from doing so?
8. What benefits would a patient receive by using the site?
9. Can you identify any risks to using the site?
10. Can you provide any suggestions for improvement(s) to the website?
11. Do you have any suggested changes to the website?
12. What do you think of this type of initiative provincially? Is there a good example of a similar initiative nationally?

## Appendix L

### Living Well with Heart Failure NING site

The screenshot shows a web browser window displaying a forum post on the 'Living Well with Heart Failure' NING site. The browser's address bar shows the URL 'livingwellwithheartfailure.ning.com/forum/caregiver'. The site's header includes a navigation menu with 'Home', 'My Page', 'Forum', and 'Caregivers'. The forum post is titled 'As a Caregiver you need to focus on living well' and was posted by 'Shauna Davies' on October 15, 2015, at 4:08pm. The post features a photo of a wooden sign that reads 'CAREGIVER'. The post content discusses the stress of heart disease for caregivers and provides a list of five suggestions for living well as a caregiver. The post is attributed to 'havens.michael34'. The browser's taskbar at the bottom shows the Windows logo, a search bar, and several application icons, including Internet Explorer, File Explorer, and Google Chrome. The system clock indicates the time is 2:28 PM on 4/4/2016.

As a Caregiver you need t...

livingwellwithheartfailure.ning.com/forum/caregiver

Most Visited Getting Started Suggested Sites Web Slice Gallery

# Living Well with Heart Failure

Home


My Page

Forum

Caregivers

**As a Caregiver you need to focus on living well**

Posted by [Shauna Davies](#) on October 15, 2015 at 4:08pm



by [havens.michael34](#)

Heart disease is stressful for all the people who love and care for you. To ensure that you are living well and taking care of yourself as a caregiver, it is important to:

- share your feelings with a close friend or another caregiver who can listen to your thoughts as you are not alone
- educate yourself on your loved one's condition as knowledge is empowering
- it is important that you take care of yourself by following a healthy diet and getting into an exercise routine
- find an activity that you enjoy to do and that you find relaxing. You deserve some quality time just for you
- get spiritual support from a clergy member or spiritual advisor.

More information may be found in the booklet, [Heart and stroke recovery road](#): An information booklet for heart patients and their families.

What are some things that you do for yourself to live well as a caregiver?

LINK

2:28 PM 4/4/2016







All Discussions - Forum - L... X

livingwellwithheartfailure.ning.com/forum

Most Visited Getting Started Suggested Sites Web Slice Gallery

Started by [Shauna Davies](#)

2 Replies · Reply by [Shauna Davies](#) Sep 21, 2015

## Living Well with Heart Failure

Home

My Page

Forum

Caregivers

### Traveling?

What are some tips you have for those getting ready to travel?

Things to consider before your leave:  
bring enough medication to last your whole trip and a few extra days  
pack your...  
[Read more...](#)

Started by [Shauna Davies](#)

6 Replies · Reply by [Susan](#) Aug 28, 2015

### Medications

Medications are an important part of managing heart failure. They help the heart by reducing the amount of work or by strengthening its pumping action. Your physician will determine the strength of the medication (dose) and the number of times it...

[Read more...](#)

Started by [Shauna Davies](#)

2 Replies · Reply by [Sandra](#) Aug 20, 2015

### A Healthy Diet Low in Salt

It is important to follow a balanced diet by following [Canada's food guidelines](#). Please click on the Canada's food guidelines...

[Read more...](#)

Started by [Shauna Davies](#)

4 Replies · Reply by [Susan](#) Aug 15, 2015

### Symptoms of Heart Failure

Search the web and Windows

2:30 PM 4/4/2016



Home - Living Well with ... X +

livingwellwithheartfailure.ning.com

Most Visited Getting Started Suggested Sites Web Slice Gallery

# Living Well with Heart Failure

Home


My Page

Forum

Caregivers

"I can certainly understand that. We are still in our 60s but would not travel outside Canada. My husband likes to go to Vancouver Island for part of the winter because it is green & he can get out & about easier without the cold, snow & ice. It is j..."

Aug 15, 2015

 Susan replied to Shauna Davies's discussion **A Healthy Diet Low in Salt**

"We have also found a lot more choices in the big stores for no salt added foods such as can tomatoes, can salmon, broths etc. PC Blue Menu is good but there are other brands now too."

Aug 15, 2015

Green replied to

Search the web and Windows

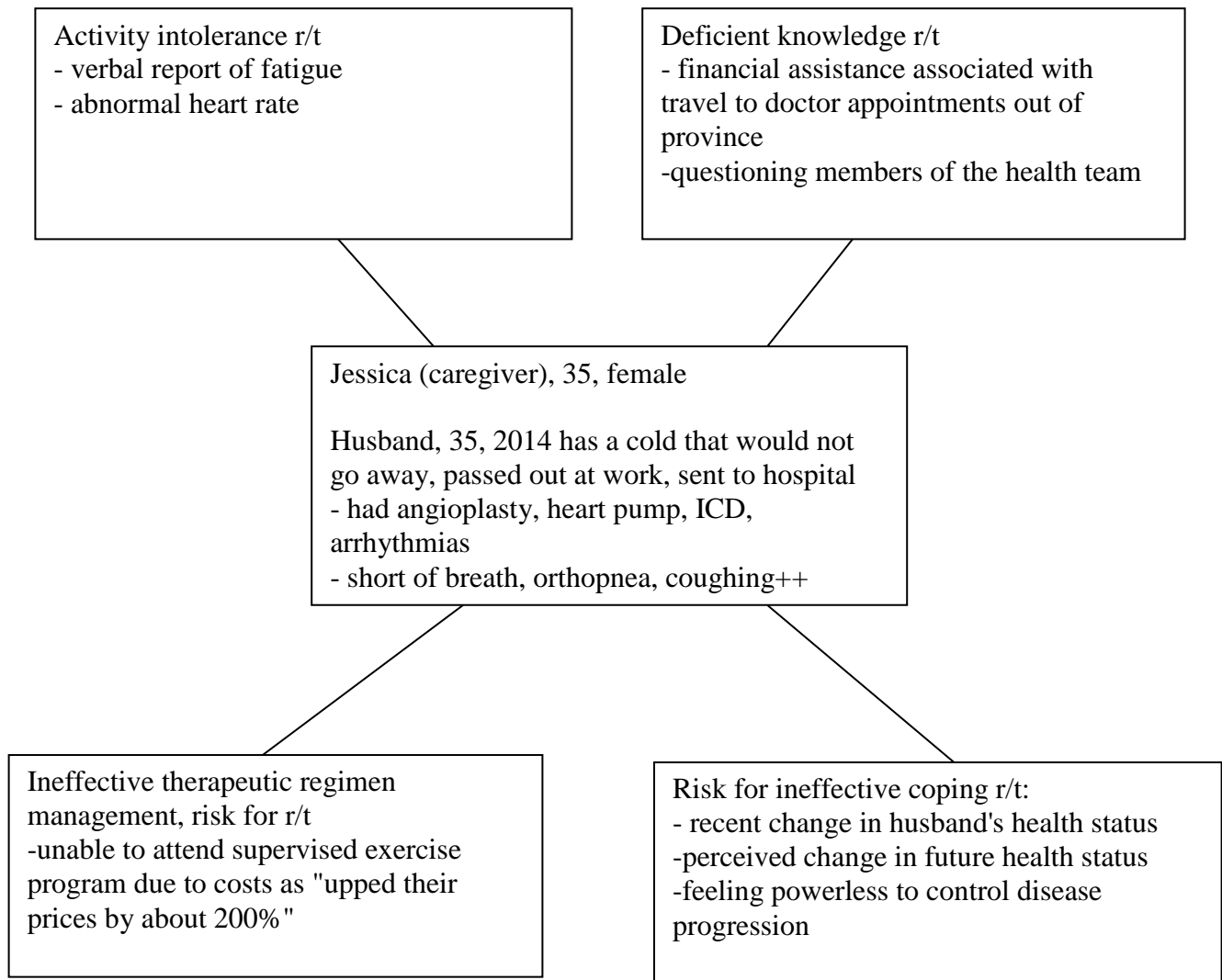
10:09 PM 6/21/2016





## Appendix M

### Nursing Concept Maps



Activity Intolerance r/t:

- verbal report of fatigue/weakness
- unable to complete desired activities
- lives in care facility to assist with activities of daily living
- exertional dyspnea

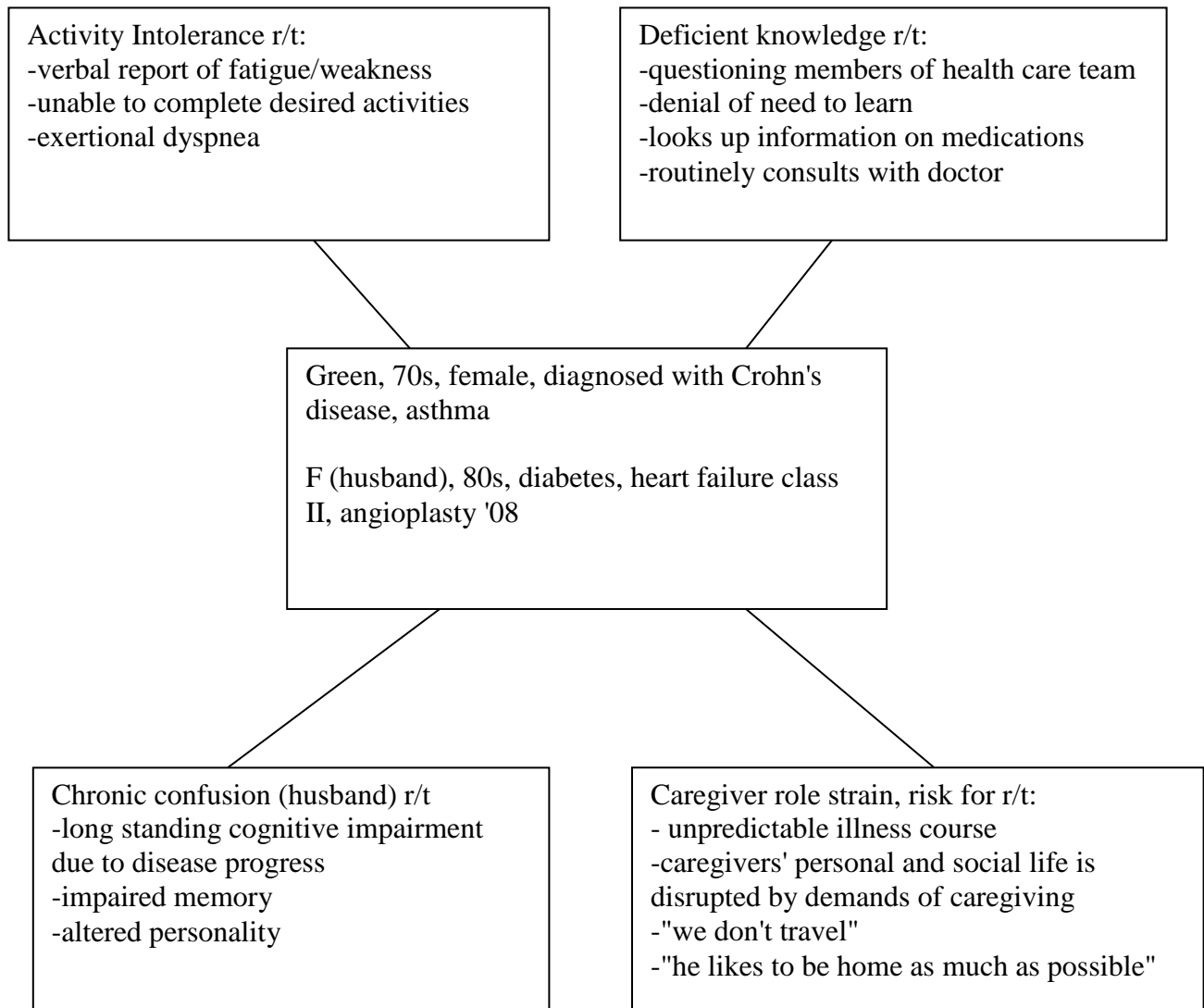
Caregiver role strain, risk for r/t:

- discharge of family members with significant home care needs. Placed in an assisted living facility.
- caregiver's personal and social life is disrupted// multiple competing roles

Lisa, daughter, mid 40s

Father diagnosed with heart failure in 2010  
class III, spouse deceased, uses scooter, lives  
in care facility





Activity Intolerance r/t:

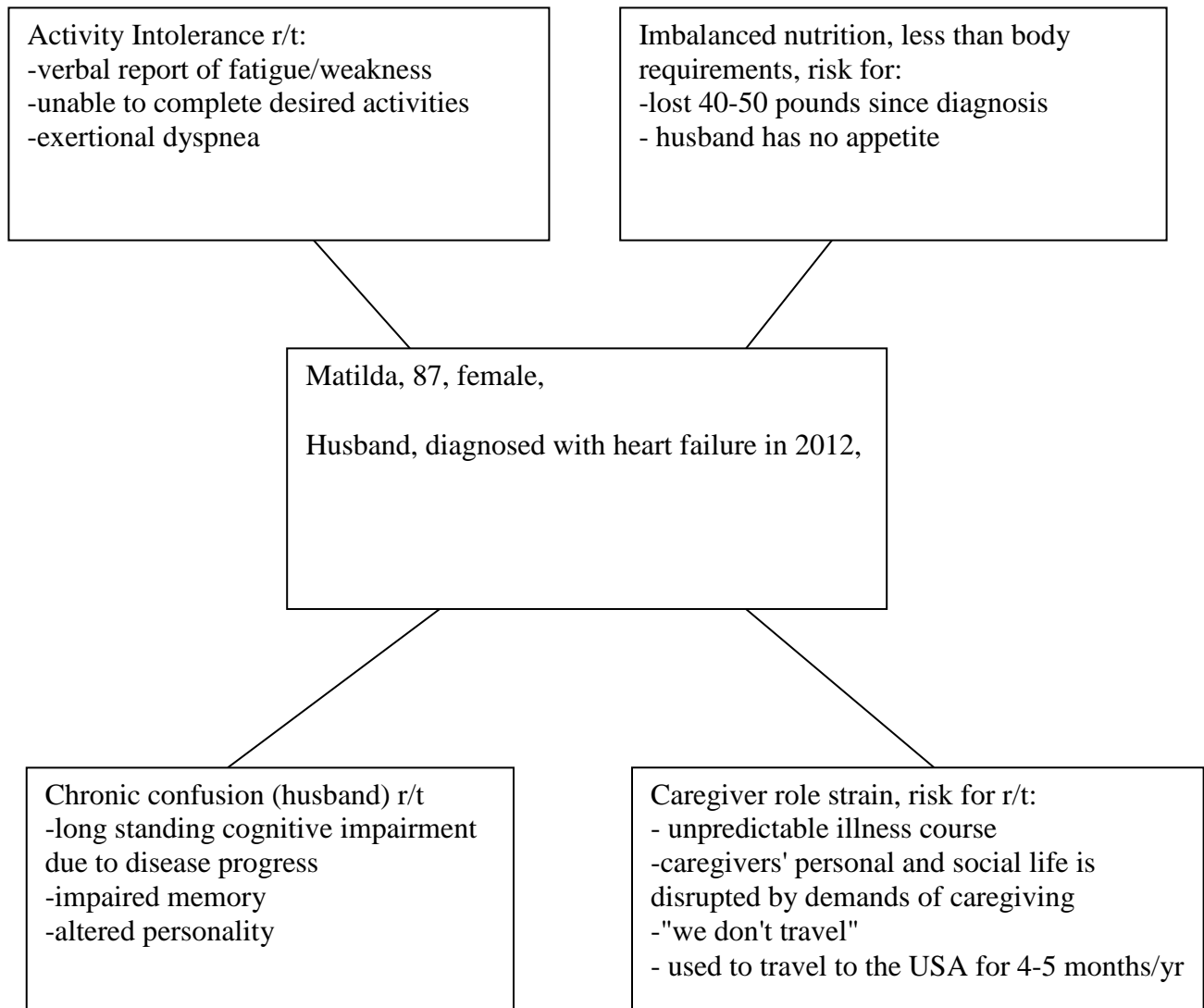
- verbal report of fatigue/weakness
- unable to complete desired activities
- exertional dyspnea
- fluid retention

Caregiver role strain, risk for r/t:

- unpredictable illness course
- caregivers' personal and social life is disrupted by demands of caregiving
- travelled in Canada
- had serious medical emergency, told not to travel

Susan, early 60s, female, retired due to husband's illness

Husband, 69, had CVA 2003, diabetes, retired farmer and outfitter



Health seeking behaviors r/t: (spouse)  
-new condition, altered health status  
-absence of interpersonal support  
-limited availability of health care resources

Spiritual distress/ Social Isolation, risk of r/t:  
- social isolation  
-husband refused to tell family his diagnosis  
-not ready to discuss/ consider Do Not Resuscitate orders

Sandra, early 60s, working part time  
Husband, 70 years, male, heart failure, class II

Deficient knowledge r/t:  
-questioning members of health care team  
-denial of need to learn  
-looks up information on medication, nutrition  
-routinely consults with doctor

## **Appendix N**

### **Caregiver Interview Guide**

#### **Collected following participation on social networking site**

Collect demographic data on sex, age, NYHA Classification of loved one (self-report, chart provided), length of time of diagnosis, relationship to the patient, how many hours a day spent on the Internet

1. What type of information do you currently have related to heart failure? Where do you access this information? What type of information do you require related to heart failure (such as information on medications, exercise, tests, travel, keeping track of changes in weight)?
2. What types of information resources do you use to find information on heart failure?
3. Are there information resources you would like to have access to that you currently do not?
4. How often do you look for health related information? (such as daily? weekly? monthly?)
5. Has the frequency you look for health related information changed over time?
6. How interested are you in a website that helps people manage their health?
7. How often do you use the internet to look up health information?
8. Any favorite websites that you use to look up health information?
9. How credible is the health information on the internet (using a scale such as 0 meaning not credible to 5 meaning very credible)?
10. Were there times you came to view the site and not respond to a post?
11. What parts of the site were most useful? What parts were not useful?
12. What benefits did you receive by using the website?
13. Any suggestions for improvement of the social networking site?
14. Why would you recommend using social networks to other?
15. Did it contribute to improvement of health behaviors? Which ones?

## **Appendix O**

### **Revised Caregiver Interview Guide**

#### **Collected prior to access on social networking site**

Collect demographic data on sex, age, NYHA Classification of loved one (self-report, chart provided), length of time of diagnosis, relationship to the patient, how many hours a day spent on the Internet

1. How do you define heart failure?
2. Please tell me about your life with heart failure and helping someone to live with heart failure.
3. What information do you currently have about heart failure?

What information do you require? (such as information on medications, exercise, tests, travel, keeping track of changes in weight)?

4. What types of information resources do you use to find information on heart failure?
5. Who do you talk to about with any questions, issues or concerns about heart failure?
6. Are there any information resources you would like to have access to that you currently do not?
7. How often do you look for health related information? (such as daily? weekly? monthly?)
8. Has the frequency you look for health related information changed over time?
9. How interested are you in a website that helps people manage their health? Are you interested in sharing your experiences with other caregivers?
10. How often do you use the internet to look up health information?
11. Any favorite websites that you use to look up health information?
12. How credible is the health information on the internet (using a scale such as 0 meaning not credible to 5 meaning very credible)?

#### **Collected following access on social networking site (first site and second site)**

13. How interested are you, as a caregiver, in a website that helps people manage their health?
14. Were there times you came to view the website and not respond to a post? If yes, please tell me why you did not respond

15. Has the frequency you look for health related information changed over time?
16. What parts of the site were most useful? What parts were not useful?
17. What benefits did you receive by using the website?
18. What suggestions do you have for changing or revising the website?
19. Why would you recommend using social networks to other?
20. Did it contribute to improvement of health behaviors? Which ones?